

Exploring the Social Context of Choking and its Implications for Care

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A thesis submitted in total fulfilment
of the requirements for the degree of
Doctor of Philosophy, Medicine

University of Tasmania
Hobart, Tasmania 7000
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December 2017



STATEMENTS AND DECLARATIONS

Declaration of Originality

This thesis contains no material which has been accepted for a degree or diploma by the University or any other institution, except by way of background information and duly acknowledged in the thesis, and to the best of my knowledge and belief no material previously published or written by another person except where due acknowledgment is made in the text of the thesis, nor does the thesis contain any material that infringes copyright.

Megan J. Hanley

14/12/2017

ACKNOWLEDGEMENTS – FORMAL

With thanks to the:

National Coronial Information System

Victorian Department of Justice and Regulation

Tasmanian Health Service

University of Tasmania

Acknowledgements – Personal

I have been privileged through this research journey to be privy to the stories of 256 at-risk adults, their informal and formal carers. I have learnt so much from them and they have become a part of my story, they have my gratitude and thanks.

Over the period of this research I have had the pleasure of being on the receiving end of the professionalism and patience of a number of NCIS Access Liaison Officers. Many thanks; you do a wonderful job in helping researchers and this one has especially benefited from your support navigating many of the processes of research.

To Dr Stella Stevens and Professor Michael Ashby, my original supervisory team who were so encouraging, thank you for the initial confidence to pursue this research.

To my speech pathology managers and colleagues, thank you for the support, listening, insights and debates, you have been wonderful sounding boards and so accepting of my ‘choking obsession’.

To Helen Howarth, Jenny Fuller and Lea McInerney thank you for being my ‘PhD buddies’ and helping me with my thoughts both abstract and concrete.

To my family and friends - thank you for never failing over all these years to ask “How is the PhD going?” A special thank you to my mum, Luceille Hanley who not only always asked but wanted the details, never knowing whether there would be a jumble of excited ‘tellings’ or a “I don’t want to talk about it” response. You navigated the ups and downs of my PhD journey with warmth and sensitivity – you are amazing.

To Professor Fran McInerney, my primary supervisor and mentor, who came late to this project but embraced the magnitude of it and my naiveté with great warmth and enthusiasm for which I will always be enormously grateful. You have taught me so much of importance. The greatest joy of this project has been working with you, your collegiate support and generosity, a professional relationship and experience I will always treasure – thank you for being you and letting me be on the receiving end of your experience, humor, compassion and prodigious knowledge of grammar!

Finally, in memory of Barry Hanley, my dad who loved challenges and was so excited about what I would learn from doing a PhD.

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ABSTRACT

Exploring the social context of choking and its implications for care

Using grounded theory methodology this study retrospectively explored the social context of choking for at-risk adults and their carers through the lens of Australian coronial reports from 2000 - 2010. The data were the police, autopsy, finding, and inquest reports compiled as part of a coronial investigation into a choking fatality, which is a reportable death in Australia. Data were obtained through access to the National Coronial Information System (NCIS).

The population of interest were adults who were clinically considered more at risk of choking than the general population. An increased risk of choking has been established in adults of advanced age and those with medical conditions associated with dysphagia (swallowing problems). Two hundred and fifty six (256) adults were identified as potentially having a predisposition to choking based on the combined criteria of age and/or medical history.

Coroner's reports have been used internationally in studies exploring choking phenomena. These studies have identified many factors contributing to choking, with the aim of reducing fatality through the control of these recognised risk factors. The clinical management of choking for at-risk adults is currently closely aligned with the biomedical model of health care and focuses on reduction of risk and death prevention for the at-risk adult. There is however, an increasing awareness that such an alignment might be too narrow to address issues arising for at-risk adults and their carers living with choking risk and its expression.

Coroners' reports are rich sources of information. They not only identify specific factors that may have contributed to a person's death but also provide insights into the social context of the death and all who may be affected by it. The social context of choking has not been widely explored, despite the contribution such knowledge could make to understanding in the area. The aim of this study was to explore the social context of choking and

its implications for care. To meet this aim, grounded theory methodology was chosen for its capacity to analyse and elucidate complex data, build understanding of multifaceted phenomena and formulate theory.

Exploration of the social context of choking identified that there are challenges for both at-risk adults and carers in this area of care which are not being addressed by current prevention-focused management. Based on these findings it is theorised that an expanded model of care is required, that includes a broader concept of 'considered support' rather than the management of risk and death prevention alone. Considered support in the proposed expanded model does not negate the appropriateness of attempting to prevent choking, but it broadens care to address the concerns of at-risk adults and their carers which fall outside the ability to control and prevent choking.

CHAPTER 1: INTRODUCTION

This study explores the social context (the people, events, actions, circumstances, structures, beliefs, feelings, consequences and more) of choking. The focus will be particularly on those adults with a heightened risk of choking (due to possible swallowing problems) and those who support them. The purpose of this study is to illuminate the social context of choking – for at-risk adults and their carers – and explore the implications for care from a sociological perspective.

In this chapter an initial basic overview of the anatomy and physiology of choking is offered, outlining a clinical perspective (focusing on the mechanics, suggested causes and initial treatment options) (Mezzich et al., 2010, p. 28) on choking. This is followed by a brief description of who oversees choking risk in people with swallowing problems and who oversees choking deaths. My own involvement with choking will then be discussed and how this lead to my interest in the social context of choking and its implications for care. Finally, an overview of each of the thesis chapters will be presented. But to begin, the anatomy and physiology of choking:

CHOKING CAN BE FATAL...

Anyone can choke; it is a reality of human anatomy and physiology.

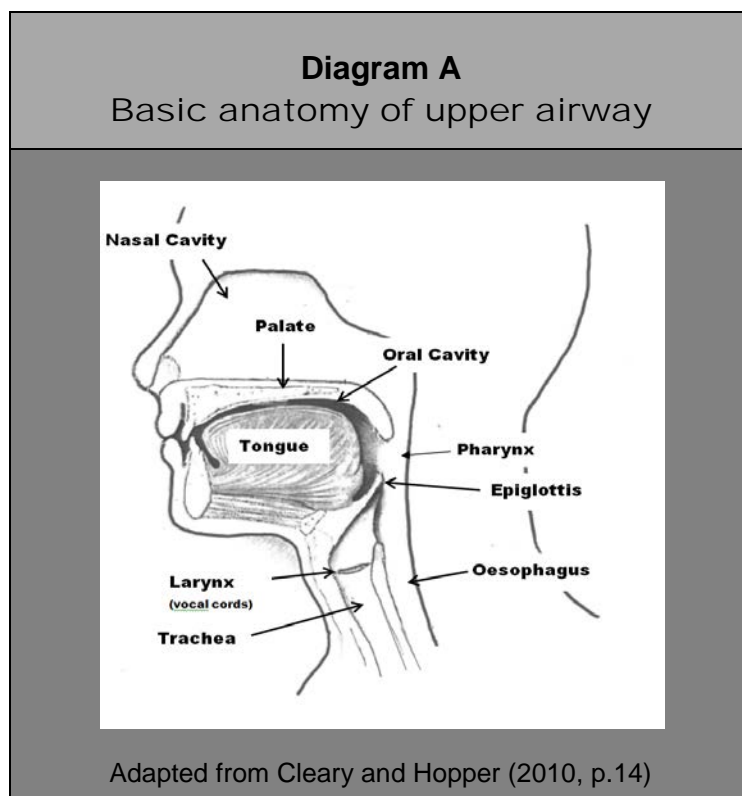
The Mechanics

Breathing and respiration

The respiratory system is made up of the airway, the lungs, and respiratory muscles. Simply described, air enters the body through the mouth or nose (drawn in through the action of inspiration using the respiratory muscles – diaphragm and intercostals) and is transported to the lungs through a series of passageways starting with the pharynx or throat area (this can be partially

visualised at the back of the oral cavity). The pharyngeal passageway then divides into the trachea (windpipe) lying at the front of the body and oesophagus (food pipe) which lies behind the trachea (Cleary & Hopper, 2010).

Diagram A illustrates the relevant structures in the head and neck area:



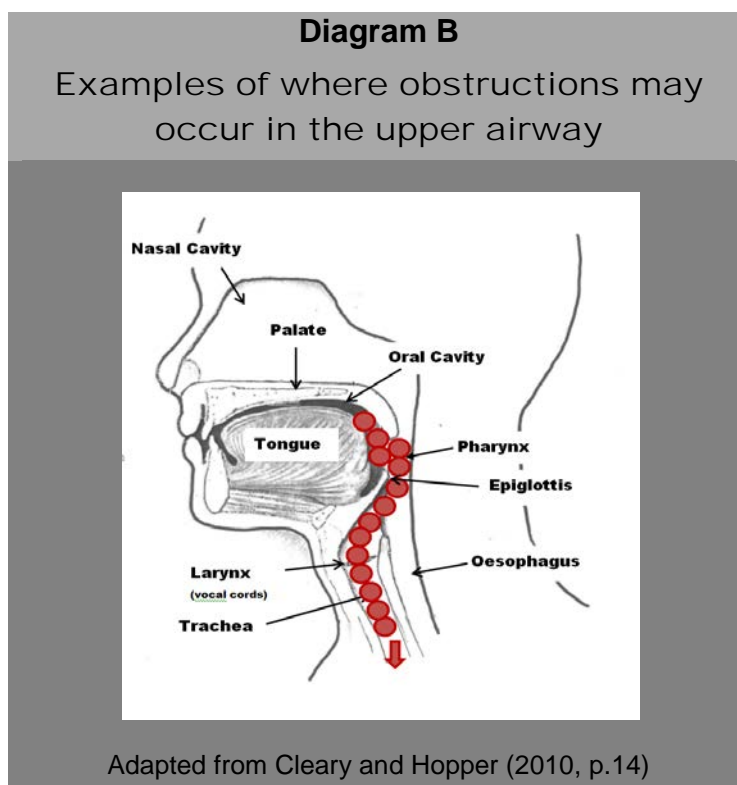
Air travels down the pharynx into the trachea (the entry to the oesophagus is closed when breathing). Air continues down the trachea, passing through the open vocal cords into two further passages (bronchi, which then divide further into smaller passages) which deliver air into the lungs (the process of ventilation) (Cleary & Hopper, 2010).

On reaching the lungs, oxygen diffuses from the air into the blood (gas exchange), the blood delivers the oxygen to the tissues in the body (gas transport), and the cells of the tissues uptake the oxygen and use it for energy production; a by-product of this final process is carbon dioxide. Carbon dioxide follows the above process in reverse to be expelled from the

body when the respiratory muscles relax (Graham, Denton, & Sandomirsky, 2016). If problems arise in any of these steps of breathing and respiration, the organ most vulnerable to lack of oxygen is the brain (Graham et al., 2016). If not rectified within minutes, damage to the brain can occur and death may result (Sayre, 2005).

Choking occurs when something becomes lodged in the throat or windpipe and restricts or blocks the flow of air to the lungs.

Diagram B illustrates the possible locations of a partial or full obstruction in the upper airway:



What people choke on is diverse and can include food (of any type or consistency), pills, fluids, secretions (nasal, saliva), dentures, other objects (wine cork, latex glove, hair ornament, dead mouse) and vomit (Berzlanovich, Fazeny-Dörner, Waldhoer, Fasching, & Keil, 2005; Dolkas, Stanley, Smith, & Vilke, 2007; Langlois & Byard, 2015; Leadbeatter, 1989; Soroudi et al., 2007;

Wick, Gilbert, & Byard, 2005). If not cleared, an airway obstruction can be fatal.

Responses to choking

Obstructions can occur at the back of the mouth, in the pharynx, or trachea, and can be either partial or full blockages. A *partial obstruction* can vary in degree and severity, but is characterised by some air still being able to pass to and from the lungs, be that around or through the blockage. A partial obstruction is not usually considered as immediately life-threatening¹ and can often be expelled by the person with coughing. Coughing is the first line of defence where there is sufficient sensory and motor capacity. In some situations however, the application of choking first aid or more advanced interventions may be required to remove an offending blockage (Australian Resuscitation Council, 2016).

A *full obstruction* is a total blockage which prevents air entering or being expelled from the lungs; coughing is not possible. It is an immediately life-threatening situation, requiring intervention from another in the form of aid to remove the blockage. This aid is usually initially via the application of choking first aid techniques; currently in Australia this includes blows administered between the shoulder blades and chest thrusts² (Australian Resuscitation Council, 2016).

If such aid is not sufficient in removing the blockage then advanced assistance by trained medical personnel, using sophisticated medical equipment, may be required. Aid for a full obstruction is extremely time-sensitive; if the blockage is not removed within minutes the brain will be starved of oxygen, causing damage and the increased likelihood of death (Soroudi et al., 2007).

¹ A partial obstruction can progress to a full obstruction.

² Techniques may vary depending on country and temporal context; in Australia chest thrusts are currently used but previously lateral chest thrusts and the Heimlich Manoeuvre were recommended and taught.

A choking event therefore, can be caused by a partial or full obstruction; range from mild to severe; be resolved by coughing (partial obstruction), a judicious hit between the shoulder blades (partial or full obstruction), or require advanced medical assistance; and can either be completely resolved, cause brain damage, or result in death.

Why people choke

As flagged above, from a purely anatomical-physiological perspective, why people choke has two simple answers: because of human anatomy (the possibility of cutting off an air passageway with a blockage) and because something creates a blockage. The why and how 'something' becomes a blockage in the airway is far more complex. A wide range of possible reasons or factors has been suggested for why adults (the age group of interest in this study) choke, including excessive alcohol intake, poor dentition, fast eating, medication side effects, the dislodgement of dentures, and cognitive problems (Cleary, Kizar, Kalra, & Johnston, 2008; Hashmi, Walter, Smith, & Latis, 2004; Kumar, Venkatesh, & Jagannatha, 2008; Warner, 2004). Thus choking events and fatalities are recognised as multi-factorial and complex in nature (Roy, Stemple, Merrill, & Thomas, 2007; Thacker, Abdelnoor, Anderson, White, & Hollins, 2008). According to a number of leading fatality studies, over 50% of adults who fatally choke on 'foreign bodies' (food, drink, objects) have medical conditions associated with dysphagia³ (Dolkas et al., 2007; Wick et al., 2005). Swallowing problems are thus considered a primary risk factor for choking.

Swallowing, breathing and choking

As noted, owing to the inter-relationship of structures, swallowing and breathing have an intimate physiological relationship. Swallowing is a highly complex process. Twenty six muscles and many nerves (which send sensory and muscle movement instructions to and from the brain) are involved in the processing and safe transference of items through the mouth and pharynx

³ Dysphagia is being defined in this study as difficulties eating and swallowing (Paik, 2012).

into the oesophagus; an action that includes protecting the airway from misdirected items through a variety of mechanisms (Speech Pathology Australia, 2014). The following basic description inevitably belies the complexity of the process, the large body of work that exists exploring and illuminating this complexity, and the ongoing work being done to further explicate it (Cichero & Murdoch, 2006; Leopold & Kagel, 1997; Matsuo & Palmer, 2009). However, for the purposes of illustrating the fundamental interconnectedness of breathing, swallowing and choking, what follows is an elementary sequential (oral, pharyngeal, oesophageal) phase description, which includes some of the key features important when considering why choking may occur.

The oral or mouth phase (phase one) of swallowing prepares an item, food or fluid for swallowing. In the case of food in particular, this includes breaking the food up (with teeth and/or tongue), saturating it with saliva, forming it into a ball (bolus) and propelling it to the back of the tongue so the swallow reflex can be triggered. While something is being processed and contained in the mouth, breathing continues, with air flowing through the pharynx at the back of the oral cavity (Cichero & Murdoch, 2006).

The pharynx (described previously) is a key feature; a shared passageway for air, nasal secretions (draining from the sinus area down the back of the pharynx on the way to the oesophagus), food, drink, saliva, or any object that might enter the mouth and intentionally or otherwise pass down the back of the throat. Its tube-like structure is not rigid; it dilates to maintain a clear route when air is passing through it but constricts when it changes roles and needs to move something down into the oesophagus as a part of swallowing (Matsuo & Palmer, 2009).

When the swallow reflex is triggered (phase two) the pharynx's role changes; breathing is suspended for approximately one second while the food or drink is being transported to the oesophagus. In this very short period of time multiple things have to happen, including the engagement of mechanisms that protect the trachea from food or fluid falling into it and the opening of the

oesophagus so the food or fluid can be propelled into it. On reaching the entry to the food pipe, the oesophageal phase begins (phase three) as food or fluid passes through it on its way to the stomach and breathing is restored (Cichero & Murdoch, 2006; Matsuo & Palmer, 2009).

Swallowing and breathing, while separate functions, are interconnected; breathing has to be suspended to make swallowing possible and swallowing has to be efficient to not disrupt breathing. If any of the phases of swallowing are impaired, items that should be processed and/or moved easily and safely down the pharynx and diverted away from the trachea into the oesophagus may not be. These items can then potentially lodge at the back of the mouth (hypopharynx), in the pharynx, or in the trachea (above or below the vocal cords), creating an obstruction that prevents air moving freely in and out of the lungs and impacts on all the steps of breathing and respiration⁴ (Graham et al., 2016).

Anne and Beth, participants in a study exploring how swallowing capabilities change with age for people with cerebral palsy, reported on how it felt to choke; both the fear and embarrassment associated with it. Anne was reported to have mild swallowing problems:

“I have [choked] a couple of times. I thought I was choking to death, but it’s a matter of getting it back up again. But the last time I remember doing it was a bit of egg or peas or something like that. It’s a very frightening experience” (Balandin, Hemsley, Hanley, & Sheppard, 2009, p. 202).

Beth was reported to have moderate swallowing problems:

“The other day I was trying to eat a piece of meat and it got caught in my throat. I managed to get it down but it was an effort. It was frightening; thank heavens it went down without me having to go to hospital. I felt awful because everyone was staring at me. I had two staff members trying to get it down, I eventually won, but it was a real fright” (Balandin et al., 2009, p. 200).

⁴ Another related bodily function that uses some of the same anatomical structures as breathing and swallowing is vomiting. Vomit, especially in large volumes if not expelled efficiently via the oesophagus, pharynx and mouth, can also block the airway and impair or prevent breathing.

Martino and colleagues (2010) captured even more experiences of at-risk adults living with choking in their study on psychological issues related to dysphagia. The following comments were made by participants:

“You can last without food for a while. But coughing and choking is right then – you can’t breathe. It certainly is not the way I want to die. That’s awful. I’m afraid of dying, let’s put it very simply” (Martino, Beaton, & Diamant, 2010, p. 28).

“I’m picking my foods differently because some are harder to chew. So I’m eliminating some that I should be eating (for nutritional value). Everyday I avoid eating alone...I mean if it’s something I know I can handle, my oatmeal or something, I would...but nothing that I think might cause me to easily obstruct – like an apple. I don’t want to go out with my friends or family for dinner unless we’re going to a restaurant real close to the hospital. Just in case” (Martino et al., 2010, p. 32).

These comments suggest just some of the complex social aspects of choking which will be encountered and explored throughout this thesis.

Dysphagia

“Dysphagia is the medical term for difficulty or inability to swallow...Dysphagia may present as difficulty with sucking, swallowing, drinking, chewing, eating, controlling saliva, taking medication or protecting the airway” (Speech Pathology Australia, 2012, p. 8). Depending on the underlying cause/s, dysphagia can impact on any or all of the outlined phases of swallowing, and can be mild, moderate or severe. While choking is frequently listed as a possible consequence of swallowing difficulties in the dysphagia literature, research specifically on choking and its relationship with the different phases of swallowing or type or severity of dysphagia, and hence the degree of related choking risk, is limited (Samuels & Chadwick, 2006) but being explored in some studies (Ekberg & Feinberg, 1992; Feinberg & Ekberg, 1990; Fioritti, Giaccotto, & Melega, 1997; Hadjikoutis, Eccles, & Wiles, 2000; Samuels & Chadwick, 2006).

Dysphagia – a medical condition in its own right – is also linked with many other medical conditions and advanced age. Presbyphagia (changes in swallowing due to normal ageing) may predispose older adults to dysphagia, especially if other conditions are present (Cleary & Hopper, 2010; Ney, Weiss, Kind, & Robbins, 2009). Many conditions associated with dysphagia have been identified in both fatal and near-fatal choking studies (Dolkas et al., 2007; Ekberg & Feinberg, 1992; Wick et al., 2005). Conditions and illnesses associated with dysphagia can be congenital (such as cerebral palsy) or acquired (such as a stroke or throat cancer) and be acute, chronic, or degenerative (Cichero & Murdoch, 2006).

Certain conditions, such as mental illness, dementia, Parkinson's disease and intellectual disability, have been particularly identified as associated with choking fatality (Kramarow, Warner, & Chen, 2014; Samuels & Chadwick, 2006; Wang, You, Chen, & Cai, 2002; Warner, 2004). Studies exploring fatal and non-fatal choking events in different clinical populations such as stroke and motor neurone disease postulate that choking may be an under-diagnosed clinical issue in these populations (Finestone, Fisher, Greene-Finestone, Teasell, & Craig, 1998; Hadjikoutis et al., 2000). People with dysphagia may experience frequent choking events of varying severity (Ekberg & Feinberg, 1992; Finestone et al., 1998; Hadjikoutis et al., 2000) or never report difficulties with obstructions. Paradoxically, choking could be the first sign that draws attention to a possible underlying swallowing problem.

Dysphagia is considered a significant indicator of choking risk. Thus adults with a predisposition to or the presence of dysphagia due to certain medical conditions or advanced age are an identifiable clinical population who potentially are at heightened risk for choking. It was the experiences of these 'at-risk adults' and those who might support them that this study was designed to explore.

Overseeing of choking

The overseers of choking risk

Many of the medical conditions associated with dysphagia are complex. Many health professionals (including medical specialists, general practitioners, nurses, and allied health professionals) may be involved in trying to support the person to manage the difficulties of such conditions. In Australia, speech pathologists have recognised expertise in identifying, assessing, treating, and recommending compensatory strategies to manage dysphagia (Balandin et al., 2009). The primary goal of dysphagia management is to reduce the risks of aspiration, malnutrition, dehydration and choking (Speech Pathology Australia, 2014). Strategies used to manage dysphagia will depend on the type of swallowing problem and other factors such as cognitive or physical disability which may impact on safe and comfortable ingestion.

Dysphagia management strategies may include texture modified diets⁵, using multiple swallows to clear food from the pharynx, positioning the person correctly for safe swallowing, having skilled feeding assistants, and/or providing supervision (Chadwick, Jolliffe, & Goldbart, 2003). Such strategies are assumed to have a positive, risk-reducing effect on choking. The person with dysphagia may or may not need assistance in applying the strategies that are relevant to them.

⁵ In Australia there are national standards for texture modification of food and drink used to manage dysphagia and its associated risks. The three levels of texture modification for food are soft, minced and moist, and smooth puree. The three textures for fluids are mildly thick, moderately thick and extremely thick. The textures are defined and apply to all food and fluids, across all food groups and meals. A client with dysphagia may be recommended a texture-modified diet of moderately thick fluids and pureed food to prevent aspiration, reduce choking risk or events and maintain sufficient nutrition and hydration without having to resort to non-oral feeding. While there is a strong focus on using texture-modified diets to reduce or prevent risks, they also often make eating and drinking more comfortable for the person with dysphagia (Dietitians Association of Australia & The Speech Pathology Association of Australia, 2007). In 2018 new international standards are in the process of being introduced in Australia (Cichero et al., 2013) but are not relevant to the temporal period of the data presented in this study.

Texture-modified diets are viewed as a therapeutic intervention, as they are recommended by a speech pathologist or doctor based on the diagnosis and assessment of dysphagia. They require a systematic alteration of all food and drink, eliminating certain textures and foods/drinks from the person's diet. They are highly restrictive and should only be applied based on clinical need.

If they do require assistance, many people may be involved in helping them manage their dysphagia and choking risk. Depending on their difficulties and where they reside (at home or in assisted-care settings, such as aged care facilities and group homes), informal carers such as family or friends, or formal carers such as personal care assistants, nurses, or catering staff may be involved in preparing food, feeding or assisting them and/or managing choking events should they occur. These 'at-risk adults' and those who support them therefore may find themselves living with a heightened possibility of choking (choking risk), recurring choking events (expression of risk), and the possibility of death from choking (consequence of risk).

The overseers of choking deaths

Choking has a unique position in dysphagia care. Unlike dysphagia's other risks, choking is potentially immediately life-threatening. If death does occur it will be investigated by the coroner, with those involved questioned by police, as choking is a reportable death in all Australian states. While legislation varies depending on jurisdiction, the coroner investigates choking fatalities because they meet one or more of the following criteria: the death was unexpected; the death occurred in care; or the cause of death could not be determined. It is the responsibility of a coronial investigation to determine the identity of the person who has died, the cause of their death, and the circumstances surrounding their death (Freckelton & Ranson, 2006).

As a part of these investigations, police will attend the place of death, question witnesses, examine the scene, and report to the coroner. An autopsy and toxicology screen may take place. After gathering initial information, the coroner may put forward a finding or request that an inquest take place. At an inquest, further information is gathered and witnesses questioned in the coroner's court. Based on the inquest, a finding will be made and the coroner may include recommendations to prevent similar deaths in the future (Hanawalt, 1991). An inquest can occur many months after the death itself.

A coroner's investigation or its possibility can be stressful for family and all others involved. Despite its focus on prevention of death rather than criminal inquiry and allocation of blame (Freckelton & Ranson, 2006), it has gravitas and procedural processes that imply at least the possibility that something untoward may have happened. Irrespective of the quality of care provided, a choking death may generate profound disruption:

After a resident at an aged care facility fatally choked during the evening meal, five police in full forensic gear arrived, cordoned off the area with crime scene tape and questioned staff late into the night (visiting some staff at their homes). The staff reported "We felt like criminals".

(Researcher practice note)

When Anise⁶ choked in a psychiatric facility, her body lay in the dining room area for seven hours while police took photos and investigated. Staff reported "We just had to work around them and Anise's body".

(Researcher practice note)⁷

While it is not the role of the coroner to judge, judgements may be implied or perceived in recommendations and comments made in the coroners' findings (Scott Bray, 2010). As a consequence of what is uncovered in a coronial investigation there is the further potential for community censure when elements of choking stories are reported in the press. This is illustrated in the following newspaper captions above reports of coronial investigations: *Left to die: Coroner slams home over choking death* (Rae, 2008, July 9); and *Dementia patient 'who could not swallow' choked to death on yoghurt fed to him by care home worker* (Culley, 2015, July 30). Judgements about care, in particular failure to reduce choking risk factors, also find their way into civil courts, with censure and large financial settlements from American cases reported (Snyder, 2010a, 2010b; Tammelleo, 2010; Tanner, 2010). Thus choking has potentially significant consequences for everyone involved.

⁶ Identifying details have been removed or changed in all researcher notes to maintain confidentiality.

⁷ Researcher practice notes are those derived from reflections on my speech pathology clinical practice.

MY INVOLVEMENT WITH CHOKING

Choking forces us to face the very real possibility of death, and fear of death in ourselves and others (Mims, 1998, p. 27; Nuland 1993, p. 160). For most of us, choking as a possibility sits outside of everyday awareness; only coming to the fore when something gets stuck in our own throat, or we see it happen to someone else, or we are told of someone else's bad experience with choking. Personal experiences of choking can be confronting and may make us modify our behaviour depending on what we think caused the problem, such as not chewing sufficiently, or eating too fast. In most cases our experience of choking, if not a major incident, will retreat into the background as an issue that may never occur again. For adults with a predisposition to choking and those who support them however, choking may be an ongoing issue that is present on a daily basis whenever food is consumed, and may generate a host of fears about death and other consequences (Martino et al., 2010).

My career as a speech pathologist began in the early 1980s. I worked in a rehabilitation setting; supporting adults who had swallowing or communication problems due to a range of causes such as stroke, motor neurone disease or head injury. My role as part of a multi-disciplinary team was to assess, diagnose, and treat or manage dysphagia and by so doing help address its associated risks, including choking. This role was aligned to the traditional biomedical model of health care which emphasises the elimination or control of disease and disability, focusing on the cause, prevention and cure of the presenting problem (Larson, 1999).

At the time if I had been asked, I would have probably supported the notion that choking came with absolutes, including: choking can be fatal; choking is frightening; and choking first aid is easy to apply. As a speech pathologist I would probably have added: risk factors for choking need to be identified and eliminated; the role of speech pathologists is to help reduce choking risks; texture modified diets can reduce the risk of choking; and choking deaths can be prevented.

With the benefit of clinical and research experience, and penning my thoughts now at the conclusion of this study, the only absolute I would claim with any confidence is that choking can be fatal. But in my early years as a speech pathologist I would have, with a sense of conviction, promoted the other ideas as truths on which one could base clinical practice.

My certainty about what I thought I knew about choking and its control however started to unravel in the late 1980s when I took on a new role. The new role was providing education, training and advice to those who provided care (informal or formal) to people with swallowing and communication problems living in the community. People living in the community included those living at home or in assisted-care settings such as aged care facilities, group homes or hostels. Carers could be 'informal' such as family members, friends or volunteers, or 'formal', meaning those employed to provide support such as personal care assistants, catering staff, nursing, medical and allied health staff, or managers of facilities.

The development of this new speech pathology role was based on community requests for more knowledge and education about swallowing and communication disability. For dysphagia care this included: helping carers providing direct care understand the risks of swallowing problems (including choking); discussing strategies that could assist someone with dysphagia (texture modified food, correct positioning); and assisting carers to develop expertise in assisted feeding and the preparation of texture modified food and drinks. It also included providing indirect carers (co-ordinators, managers) in assisted-care settings with knowledge to develop policies and procedures to address dysphagia management. Additionally, it provided all carers with an opportunity to share the multiple challenges they experienced in supporting someone with dysphagia. It was a unique position which partially acknowledged a broader, social aspect to dysphagia care. Nevertheless it was focused – at least initially – on training people to reinforce a clinical perspective of management and prevention of risk.

Training by its nature implies one person has skills and knowledge which they impart to others who hopefully want them. Little did I know at the outset in this new trainer role that the participants attending training (both informal and formal carers) would gently and at other times brutally teach me that the ordered, predictable, and controllable situations and techniques of my biomedical training in dysphagia care often did not translate well into their social reality. Choking management – a subset of dysphagia care for me as a speech pathologist – was often a primary concern and fear for those caring for people with swallowing problems. Over time it became a primary concern for me also, as the complexity of the topic unfolded in many training and consultation incidents.

Three incidents stand out as influencing my thoughts and feelings about choking and its implications for care. The following situation made me question just how far management of risk should be taken and how lost we can get in balancing quality of life considerations (illustrated here in outings, eating and socialising) with clinical care and expediency:

Asked to provide choking management training for staff at an aged care facility I arrived after a two-hour drive to find staff were unavailable as they had taken residents out to see a community event. The acting Director of Nursing (DON) took the opportunity to ask me what it would take to give all the residents with dysphagia at the facility feeding tubes⁸. Her rationale was that such an action would prevent choking and make the feeding of these 'difficult' residents easier as they could be placed on feeding regimens (which she had experience of from acute care practice), thus ensuring adequate nutrition, reduced feeding time, and significantly reducing staff stress.

(Researcher practice note)

Embedded in this DON's question was a practical, problem solving response to a number of the issues inherent in choking and dysphagia management: the difficulty of feeding people with dysphagia; the risk of choking, malnutrition and dehydration; the possibility of death; the ramifications of not reducing these risks; limited staff resources and time; and staff stress. The

⁸ Percutaneous Endoscopic Gastrostomy or Naso-gastric tubes.

potential benefit to residents of seeing and being part of a community event seemed prioritised in this care setting, but the psychosocial wellbeing of residents somehow became lost when choking, reducing risk and 'getting the job done' came to the fore. I was appalled by the solution suggested to manage the challenges but also sympathetic to the concerns, frustrations and fears I felt were behind it.

Listening to people talking about choking events and their impact was often painful. I remember vividly the anger, tension and distress that filled the room at a staff debriefing for three community support workers⁹ after Clyde (one of their clients) choked:

Clyde was a client with multiple sclerosis who had physical difficulties which made it difficult for him to feed himself. The three community-based carers prepared meals and regularly fed Clyde in his home. One lunchtime, Clyde choked on the steak and broccoli which had been cooked and given to him by Astrid, the carer on duty. Astrid tried to relieve the blockage by applying basic first aid and called the ambulance. It was a severe choking event that could have resulted in death. As a result of Astrid's quick actions however, Clyde received additional treatment, was taken to hospital and survived.

In the subsequent staff debriefing provided by the care organisation, it was revealed to Astrid and her colleagues (confidentiality had previously prevented the disclosure) that Clyde had swallowing problems. He had been assessed by a speech pathologist as requiring a minced and moist diet¹⁰ for safety. Clyde and his wife had discussed the treatment recommendation and decided to refuse it as Clyde wanted to maintain as normal a life as possible. They in no way held Astrid responsible for what had happened and were very appreciative of her prompt action. They wished for care to continue as previously.

All three carers were very fond of the client and his wife. All three however expressed feelings of anger and

⁹ Employed by a community based care organisation, the role of the support workers (who have nationally accredited certificates in aged or disability care) was to provide assistance to clients with disabilities with the tasks of daily living which could include bathing, dressing, shopping, preparing meals and assisting a person to eat or drink as required.

¹⁰ On a minced and moist diet, the steak and broccoli would have been minced (particle size 0.5cm or less) with liberal amounts of sauce or gravy over it.

betrayal at not being informed of the risks their client faced. After discussion, one carer was happy to return to her previous care duties, feeling comfortable with the client's decision despite the possibility of future choking events. The second carer would only return to the care situation if another carer or the wife was present at meal times to provide additional support. Astrid, who had so successfully handled the emergency event but been traumatized by it, refused to return to the situation. She felt that she had, without her permission, been made complicit in a decision and action that could hasten Clyde's death.

(Researcher practice note)

Astrid, ignorant of the risk, had been additionally required to respond to the choking event without any opportunity to prepare for its possibility. Clyde's choking risk and the decisions he made in relation to it were his to make. The care organisation had respected his privacy and confidentiality. Others however had been affected by what occurred. These experiences and others did not fit neatly into the clinical response of identifying risk factors and making recommendations to reduce them. Choking generated ethical issues which prompted me to pursue a Masters of Bioethics which I completed in 2007. I suspect, grappling with the challenges of choking, I was trying to replace the comfort of the known biomedical framework of care which did not seem to be working with a bioethical one. The challenges continued however. The pragmatism and courage of Evelyn will always remain with me:

Evelyn's husband was a force to be reckoned with, and was not interested in changing what he ate or his previous eating behaviours in response to swallowing problems after a stroke. As was his habit he would eat in bed at night, with Evelyn in another room reporting that she often heard him coughing and feared that he would choke on his nocturnal snacks. Evelyn came to an offered first aid session on 'how to manage a choking event' should she be present if an event occurred. She showed admirable competency in applying all the techniques but lingered afterward without any apparent diminishing of the high anxiety she had arrived with. Gentle probing revealed that Evelyn accepted her husband's lifelong eating habits and that he might choke and there would be nothing she would be able to do. What she was really

frightened of what she would find in the morning if he choked during the night. Evelyn had never seen a dead body. Outlining what she would be likely to see after a choking death and who to call, a much less anxious Evelyn left the session.

(Researcher practice note)

Evelyn was able to articulate what it was that she most feared about choking.

The desire to avoid choking events by hooking at-risk adults up to feeding tubes, the respect for the privacy and confidentiality of a client but at the cost of a carer's wellbeing, the fear around what death looked like – these were aspects of choking that went well beyond the clinical identification and management of risk factors. Choking had a social context; a context which both impacted on risk reduction and involved more than the at-risk adult.

THIS STUDY

We can all be ambushed by choking and the challenges it presents. Choking is confronting and complex. The identification of risk factors and their reduction and control may not be enough to address the needs of at-risk adults and those who care for them. Choking has physiological mechanisms, however these frequently manifest in a social context, made up of people, events, actions, circumstances, beliefs, feelings, consequences and much more. The social context of choking has not been studied in depth; the purpose of this study was to understand more about the social context of choking and its implications for care for at-risk adults and those who support them.

Coronial reports are a common data source used by choking studies focusing on the identification of risk factors and their control. They are a rich source of information and often capture much of the social context leading up to and surrounding death (Scott Bray, 2010). This study used coroners' reports as the data source to explore the social context of choking. To capture the social context and explore what it could tell us about care, classic grounded theory

methodology was chosen for its capacity to analyse and elucidate complex data and build understanding.

Overview of the thesis

Chapter 2: Literature review

The literature review (completed near the conclusion of the study in keeping with the chosen methodology) presents an overview of the evolution of thought around choking and its management over the past 250 years. It outlines the historical roots of choking research, and the influences that have shaped the current care paradigm with its focus on intervention and prevention. It will also provide a brief overview of some of the current challenges to the application of this approach and where this study sits in relation to both the historical perspective and the contemporary space which has begun to explore the social aspects of choking.

Chapter 3: Methodology

This chapter outlines the methodology and method used to explore the social context of choking and its implications for care. This study used the methodology of classic grounded theory developed by Glaser and Strauss (1967) because of its ability to elucidate complex issues and formulate theory from data. The key tenets of grounded theory are summarised and discussed. The method used to promote theory emergence from the data is described and illustrated. The framework for ethics approval and presenting the evidence is also discussed.

Chapters 4 – 7: Findings

The study findings are presented in a series of four chapters.

The first chapter (Chapter 4) of the series is divided into two sections. The first section briefly introduces 3 key categories (awareness, response and acknowledgement) and the core category (support) that together form the basis for the theory on the social context of choking being offered by this

study. How these categories are conceptualised is discussed. The second section establishes background information on the social context of choking. It describes the medical challenges at-risk adults in this study were facing. It also depicts the diverse settings where choking may take place and who may be involved.

Chapters 5 to 7 present the findings on the exploration of the social context of choking and show how the four categories emerged from the data to illuminate an expanded theory of care. The evidence for the findings is presented using a narrative framework. The social story of choking is presented through the beginning (Chapter 5), middle (Chapter 6), and end (Chapter 7) of elements of individual choking stories which have been interwoven to tell an over-arching story: the choking narrative. At the conclusion of Chapter 7, what has been learnt about the social context of choking is summarised and the study theory explained.

Chapter 8: Discussion

This final chapter encapsulates the major concerns identified in the exploration of the social context of choking. It contains a discussion of the theory proposed by this study; how it includes but expands on the current theory of choking care and connects to other approaches and theories proposed to navigate complex care issues in other, related areas, including relationship-centred care and palliative care. It also identifies the study limitations, provides an example of how the knowledge gained in the study has been applied within a clinical care context, and finally proposes recommendations for future research.

CHAPTER 2: LITERATURE REVIEW

Preamble

It is a tenet of classic grounded theory (GT) that the literature review is performed near or at the end of analysis (Glaser & Strauss, 1967). As will be explicated in Chapter 3 which addresses the study methodology in depth, the aim of this sequencing of the literature review in the research process is to give the researcher the opportunity to: initially approach data with as open a mind as possible; allow for a new perspective or theory to emerge that is grounded in the data and not in previous conceptualisations of the area under study; and provide another 'slice of data' (the literature) which can be compared and contrasted with the new theory being formulated (Glaser & Strauss, 1967). In keeping with this tenet, this literature review was performed near the end of data analysis. For presentation purposes however, the literature is placed prior to the findings chapters in order to set the stage and situate the reader (who is not required to approach the data as a GT researcher) in the extant research context/s of which the current study now forms a part.

Introduction

This literature review explores the evolution of thought around choking and its management over the past 250 years. It will briefly outline the historical roots of choking research and the influences that have shaped how we identify and respond to the many issues choking presents. The aim of this exercise is to highlight the past and current challenges we face in 'preventing and managing' choking and to explore the possibility that the therapeutic conceptualisation of choking, which has already historically undergone two 'truth-seeking' philosophical shifts, may need a third. To this end this review is divided into three sections.

The first section explores the first truth-seeking shift; from choking being a visitation from God to being within the grasp and control of the men¹¹ of medical science of the 18th and 19th centuries. It will explore the origins of choking research in the 1700 and 1800s, the goals of that research (which were diagnosis and cure), the innovations which progressed those ambitions, and the challenges that still remained by the mid-20th century.

The next section marks the second shift in truth-seeking; from focusing on cure to acknowledging the need for prevention. It will explore how by the mid-20th century, continuing fatalities prompted a new way of thinking about choking, with many researchers seeking to identify and understand the factors precipitating a choking event in the hope that they could be controlled or eliminated, and choking events and fatality prevented. This section will also discuss how the new focus on prevention coincided with the innovation of new first aid techniques and how together these changes in viewpoint and treatment significantly divided who would have responsibility for this area of care by the end of the 20th century.

The final section will reflect on the issues that have and have not been resolved in 250 years of studying choking. It will provide an overview of contemporary issues that challenge both whether prevention is possible and whether it should be the sole focus of care. It will also introduce where this current study, which promotes an exploration of the social context of choking, sits within the historical framework and the additional truths it seeks to uncover. In doing so it will suggest the likely need for a third philosophical shift in how choking is conceptualised alongside a new broader theory of care.

¹¹ Reference will be made to men in this context as women were not admitted to medical schools in the UK and US until the mid-1850s.

SECTION 1: INTERVENING IN CHAOS

In 1854 Dr Samuel Gross (1805-1884), eminent American academic and surgeon wrote:

How many persons have perished, perhaps in an instant and in the midst of a hearty laugh, the recital of an amusing anecdote, or the utterance of a funny joke, from the interception at the glottis¹² of a piece of meat, a crumb of bread, a morsel of cheese, or a bit of potato without suspicion, on the part of those around, of the real nature of the case! Many a coroner's inquest has been held upon the bodies of the victims of such accidents, and a verdict rendered that they died by the visitation of God, when the actual cause of death lay quietly and unobserved at the door of the windpipe of the deceased (Gross, 1854, p. 43).

Dr Gross's observations capture some of the features of choking (obstruction of the airway by a foreign body), that are both shocking (a sudden, unexpected death in seemingly innocuous circumstances) and challenging (the identification by others of the underlying cause of fatality). It also notes the long connection of choking deaths with coronial inquiry. The reference to God as the underlying 'causal factor', also highlights the unknown, unforeseen, uncontrollable nature of choking as it would have been experienced by many in the 1700 and 1800s. Attributing such events to God is unsurprising given what the early physicians of the 18th and 19th century faced in trying to determine the presence and effects of foreign bodies lodged in the airways (Becker, 2010). The origin of choking research (though the term 'choking' was not used to denote obstructions of the airway initially) was a subset of the larger study of the effects of *foreign bodies in the air-passages* (Gross, 1854) undertaken by physicians of the time.

¹² Opening of the larynx (voice box).

The findings and influences of the 18th and 19th centuries

The study of foreign bodies in the air passages

Medical reports of foreign bodies (FB) in the airways were noted but historically sketchy prior to the mid-1700s (Clerf, 1952; Montoya, 1986).

Those reports available, appearing in Great Britain, America, and continental Europe, were case studies which sought to identify the symptoms associated with these events, the treatments used, and the outcomes of those treatments (Clerf, 1952; Gross, 1854, p. vii).

The first noted paper on the topic was by a Dr Louis, a French doctor who had collected all the known medically reported cases at the time – only 28 in total – and presented his clinical insights at the Royal Academy of Surgery in Paris in 1759. Dr Louis's conclusions stressed the need for correct diagnosis and an 'early resort to the knife' to locate and remove the offending obstruction (Gross, 1854, p. ix). A smattering of writings on the topic appeared in the latter half of the 18th and early 19th centuries, which included airway restriction caused by FB obstructions in the oesophagus (Clerf, 1952). The seminal work on the topic however was that of Dr Samuel Gross, quoted above, many of whose insights are still relevant today (Montoya, 1986).

Uncovering the facts

Gross was a highly esteemed academic, pathologist, and trauma surgeon, who authored *A practical treatise on foreign bodies in the air passages* in 1854 (Clerf, 1952). Faced with many isolated facts on the topic, he "...found the whole subject in a state of chaos..." and set about to systemise this area of concern by compiling 200 cases (both successfully resolved and fatal) based on his personal experience and those of other colleagues at home and abroad (Gross, 1854, pp. vii-x).

Gross as a researcher set his aims high, stating that he wished to collect all the facts (of known cases), analyse and compare them with each other, and

“deduce from them such conclusions, general and particular, respecting the nature, symptomatology, pathology and treatment of foreign bodies in the air-passages...” (Gross, 1854, p. viii). This extensive investigation included foreign bodies lodged throughout the air passages (oro-pharynx, pharynx, trachea, left and right bronchi and bronchioles), in both adults and children. In systematising this area he separated out the symptoms and effects of foreign bodies which fully or partially obstructed the airway (having an immediate impact on respiration – ‘choking’) from those that lodged or moved around the airway, most frequently causing patho-physiological changes such as inflammation, ulceration, or infection over time (Gross, 1854). The focus of Gross’s work was correct diagnosis and cure.

The challenge of diagnosis

In the course of his treatise, Goss articulated what he and other early researchers were up against in illuminating this largely ignored area (Gross, 1854). Diagnosis was a fundamental issue. Inhalation of a FB was not always witnessed and when it was it was most often by medically naïve observers, making descriptions of what happened sketchy. The signs and symptoms of a foreign body located in the airway differed depending on whereabouts the foreign body was situated, and whether it was stationary, prone to movement, or obstructing. Symptoms of non-obstructing foreign bodies could fluctuate and appear days, weeks, months and even years after the offending foreign body had been inhaled. Initially non-obstructing foreign bodies could move into a narrower part of the airway, causing a blockage at any time (Gross, 1854).

Differential diagnosis of a FB in the airway, particularly in the absence of confirmation of an inhalation event, could be extremely difficult due to the similarity of symptoms with other respiratory disorders such as croup or even a cold (Gross, 1854, pp. 90, 95). At the time there was no way of viewing the airways to confirm the presence and location of a FB. Confirmation was only possible through spontaneous expulsion, surgically opening the throat area, or autopsy (Gross, 1854).

Lack of physician experience with all the possible different manifestations of FBs and the challenges of communicating individual cases studies to a wide audience were a further impediment to knowledge and successful diagnosis. Thus Gross's collection of cases and analysis were particularly significant and extraordinary.

The challenge of treatment

The challenges of diagnosis aside, the likely presence (via observed inhalation) or suspicion (via witnessing of respiratory distress) of an inhaled FB initiated a range of treatment responses. The aims of treatment were to expel the foreign substance, and to "...prevent the mischievous effects which its presence is calculated to induce in the respiratory organs, as well as the system as a whole" (Gross, 1854, p. 183). Many modes of treatment were in use and being trialled at the time of Gross's writing, which he meticulously reviewed and documented. Treatment recommendations included bleeding¹³ to manage the chronic ill health caused by a FB in situ, and close observation of the victim, who was withdrawn from the activities of normal life lest such activities caused the FB to move and become an obstruction.

Treatments to expel the foreign body which Gross reported on included: waiting for the body to naturally expel the FB (which could quickly lead to fatality when that did not occur); rubbing the neck and windpipe with liniments and ointments; swallowing almond oil and butter to lubricate the air-passages to help the FB slip out; or using substances to induce vomiting, sneezing or coughing. Suspending the patient by their heels, finger sweeps of the back of the throat, and slapping the victim on the back were also used to try to remove foreign bodies, although Gross was of the opinion that these latter treatment measures should be used judiciously, as if not applied in the appropriate situations (dependent on its location) they threatened to lodge the FB more securely and irrevocably in the airway (Gross, 1854).

¹³ Removing blood from the body.

Different treatments to extract a FB therefore varied in utility, with some (depending on the particular type and fortuitous placement) being unhelpful or more likely to exacerbate the situation (Gross, 1854, p. 52). Gross, like Louis before him, was emphatic in recommending the surgical opening of the windpipe (bronchotomy) as soon as possible in suspected choking. By the surgical means of the bronchotomy, the victim "...was recalled, as it were, from death to life" (Gross, 1854, p. 51). The bronchotomy however, was not without its problems, and as an intervention was in 1882 – nearly 30 years after Gross's recommendation – shown to have a higher mortality rate than non-interference (Clerf, 1952)!

Diagnosis and cure: The biomedical choking reality

In trying to uncover the reality or 'the truth' of choking, it is instructive to reflect on where choking research fitted within its historical context and how that context may have influenced both how it was perceived and the consequences of that perception.

Gross and physicians of his time were men of the 'new science' which evolved during the Renaissance and culminated in the 17th century (Kries, 2012). They and their initial forays into studying choking benefitted greatly from the revolution of thought and collective work of others which was the legacy of the Renaissance period (1300–1700). Failing the ability to visualise foreign bodies in living subjects, it is hard to imagine how Gross and his medical colleagues could have progressed their research without the foundation work of anatomists and physicians such as Andreas Vesalius. Vesalius in 1543, challenging Galen the 2nd century Greek physician's schema of the human body (based on animal dissection), produced the first book considered to accurately reflect human anatomy (Florkin, 2015; Vallejo-Manzur, Perkins, Varon, & Baskett, 2003). The knowledge he gained, based on meticulous dissections of the human body (previously forbidden by the church and still severely restricted in his time), further legitimised to both his colleagues and society at large this form of endeavour as key to medical education, the cure of maladies, and post-mortem diagnosis of cause of

death; pursuits critical to advancing understanding of the respiratory system and the location, effects and treatment of foreign bodies in the air passages (Sherzoi, 1999).

What is also evident in Gross's treatise is not only the gathering of all the relevant knowledge available to produce an authoritative study, but also the embracing of the philosophical underpinnings and methodology of the scientific revolution of the 17th century. Anatomical works like Vesalius's were only possible and accepted because of shifts in beliefs about the nature of man and where he fitted in the natural order. The body and soul of humans in medieval times were considered by the Christian church to be inseparable, and therefore the body was inviolable (preventing the desecration of the body through dissection). 'The new science' of the Renaissance however was instrumental in shifting this belief through the philosophy of dualism which separated the body from the soul, leaving dominion of the soul with the church and the body to the dominion of man (Engel, 1989).

This somewhat simplistic sketch of the forces of the time denies the complexity, breadth and upheaval of change, both in thinking and effect, that took place over this period and across all aspects of life. What is undeniable however, was the influence of men like Francis Bacon (1571-1626), Rene Descartes (1596-1640) and Isaac Newton (1642-1727) in changing how man was viewed in regard to his mind and body and his place in the natural order of things (Hallam, 2003; Kries, 2012). In particular, these influential thinkers and scientists, based on their own innovation and the thinking of those before them, embraced and furthered the idea that the world could be viewed mechanistically with underlying laws. By this thinking, the complexity of nature had a structured order, and if the individual parts of the structure and their relationship to each other could be identified then the whole could be understood. Through observation, experimentation and objective, rational analysis, the complex and previously unknowable would become simple and known – and controllable (Engel, 1989; Hallam, 2003).

This philosophy and its methodology was adopted by the medical fraternity; the human body was viewed as a biological machine, made up of different parts which could be reduced into their components and studied. Disease was viewed as a single causal agent which disrupted the machine; if removed the machine would return to perfect function. This mechanistic, reductionist vision was at the root of the evolving biomedical mode whose dominance persists, largely unchallenged, to the present day (Engel, 1989). The model's primary features include:

- All illness and all symptoms and signs arise from an underlying abnormality within the body (usually in the functioning or structure of specific organs), referred to as a disease
- All diseases give rise to symptoms, eventually if not initially, and although other factors may influence the consequences of the disease, they are not related to its development or manifestations
- Health is the absence of disease
- Mental phenomena, such as emotional disturbance or delusions, are separate from and unrelated to other disturbances of bodily function
- The patient is a victim of circumstance with little or no responsibility for the presence or cause of the illness
- The patient is a passive recipient of treatment, although cooperation with treatment is expected.

(Wade & Halligan, 2004, p. 1398)

The thinking of the 18th and 19th centuries and the evolving biomedical model of disease which emerged from it would have been enormously seductive at that time. It established both the potential to understand the human body and to have dominion over it through the manipulation of its parts and the control of any threatening agent.

The aim of Gross and his colleagues to relieve human suffering through the correct diagnosis and cure of foreign bodies in the air-passages could not have had a greater affinity with the mechanistic, reductionist philosophical view and consequent disease model being formed at the time. The human body as a machine, the air-passages a series of connected pipes, a foreign body entering one of the pipes, lodging itself at a particular critical juncture,

effectively clogging the ‘works’, and the successful removal of said clogging guaranteed to restore the victim to perfect health. The reality of choking was thus – unarguably – a biomedical one.

The chaos Gross faced in studying this area of ‘disease’ could be brought under control by both scientific thought and methodology. Behind an assumed visitation of God was simply a machine which had an unwanted, foreign part in it which needed to be removed. Locating where the unwanted foreign body was in the machine however, was essential for success.

Diagnosis and foreign bodies within sight and reach

The initial attempts at studying choking were complicated by its many confounding features. If the victim survived long enough to be brought to a physician, the cause of the problem would have in most cases been hidden; ‘out of sight’ of any visual and physical examination. In the first quarter of the 19th century, techniques to visualise the airways were in their infancy.

Physicians had been trying to develop techniques and instruments to view the back of the throat and larynx for diagnostic and therapeutic purposes. It was not however until 1854, the same year Gross published his book on foreign bodies in the airway, that Manuel Garcia, a Spanish singer and music teacher interested in the muscle movements used for singing, was credited with the first successful visualisation of the vocal cords and entrance to the trachea in a living person. This visualisation was made possible through a device he invented which used multiple mirrors (one of the forerunners of the modern laryngoscope¹⁴) (Bailey, 1996; Radomski, 2005). Physicians however, had to wait a further 40 years of continuing innovation which included the invention of the light bulb in 1879 and the use of cocaine in the 1880s as a local anesthetizing agent, before a workable bronchoscope came to pass. The bronchoscope was an instrument that in 1897 allowed the German physician Gustav Killian to visualise and remove a bone from the airway by passing a rigid tube via the oro-pharynx and past the larynx of an

¹⁴ Laryngoscope – an instrument that allows a direct view of the larynx (Bailey, 1996).

awake patient using local anaesthetic (Becker, 2010; Ruetsch, Boni, & Borgeat, 2001).

Slitting open the throat was no longer the only surgical option available when circumstances – a partial obstruction or non-obstructing foreign body in the air passage – afforded the time for more considered removal of an obstructing foreign body. Innovations in bronchoscopy, surgical intervention, and medical treatments (such as the advent of antibiotics in the 1940s) would progress the removal of foreign bodies in the airways and treatment of the systemic problems they could cause to good effect, and which indeed continue to this day (Becker, 2010), but in the case of foreign bodies obstructing the airways death was far from having been defeated.

Choking, a ‘visitation by God’, had been replaced with the understanding of the reality of a foreign body obstructing the airway, the facts surrounding its effects, and the possibility of interventions, if time and the availability of a physician permitted. A hundred years on however, despite Gross and his colleagues’ truth-seeking and the innovations variously prompted by or serving it, choking continued to prove fatal. The seeking of truth about the ‘reality’ of choking required another perspective; the focus on diagnosis and cure through the removal of the foreign body had not provided all the answers.

SECTION 2: PREVENTING CHAOS

The findings and influences of the 20th century

In the 20th century there was a shift in focus of the study of choking. Despite the knowledge gained in general about foreign bodies in the airways in the 18th and 19th centuries, the specific features of choking continued to challenge the medical interventionist goals of identification and cure. This prompted a philosophical shift; a second truth-seeking search for the elements that constituted the ‘reality’ of choking.

Prevention

Dr Roger Haugen, an American medical examiner¹⁵, wrote the following introduction to his 1963 report; an introduction which echoed Gross's portrayal of choking over a 100 years earlier:

A middle-aged or elderly person, at a fashionable restaurant, is partaking of filet mignon, or perhaps broiled lobster or prime rib of beef. At the same time, he is conversing with companions at dinner. Suddenly, he ceases to eat and talk. The dinner companions are perplexed but not alarmed for there is no indication of distress. Then, the person suddenly collapses at the table...The person is rushed to the nearest hospital emergency room where he is dead on arrival. The emergency room physician, or the family doctor, attributes death to natural causes and probably to coronary artery disease (Haugen, 1963, p. 142).

Increased knowledge about foreign bodies in the airways had not changed the essential features of choking. Full obstructions of the airway were still sudden and still caused unexpected deaths in innocuous circumstances. There were still problems with witnesses identifying the reason for collapse and death. In Haugen's report, which presented the findings on nine such deaths, physicians were present at two of the choking events but did not recognise them as such, instead attributing death to age and coronary artery disease. Identification and differential diagnosis difficulties, which had plagued witnesses and the physicians of the 19th century, were still proving a problem in the 20th. Choking deaths continued to come to the attention of coronial investigations, but a visitation from God as the cause of death had given way to the confirmation of an obstruction of the airway at autopsy.

Haugen concluded that, even if a food obstruction were suspected at the time of a choking event, there was little that could be done to preserve life short of medical staff being present and the possibility of a tracheotomy (surgically opening the airway below the obstruction). The need for 'the knife' mirrored the conclusions of Gross and earlier investigators.

¹⁵ A medical examiner in the American system can have the equivalent duties of a forensic pathologist or coroner in the Australian system.

First aid procedures for choking

Contextually it is important to note that Haugen was writing at a time (the early 1960s) when there was no public, comprehensive first aid procedure for choking. Aid provided by witnesses was likely to be mouth to mouth resuscitation¹⁶ in response to the person having stopped breathing (of little use given the presence of a blockage preventing air getting to the lungs) (Haugen, 1963). This was nine years prior to Heimlich describing his abdominal thrust manoeuvre to remove full obstructions of the airway (Heimlich, 1975).

The Heimlich manoeuvre, still in use in the US and the precursor to the lateral thrust and chest thrust techniques used in Australia, was the first substantial first aid innovation put forward since the experimental techniques explored in the 1700 and 1800s (Carey, 2014; Gross, 1854). Interestingly, some of the basic thinking around the mechanics of the Heimlich and chest thrust was apparent in the experimentation done by physicians and individuals at the time of Gross's work, which were briefly documented but not rigorously pursued (Gross, 1854), perhaps partially because of Gross's strong push for surgical intervention at the time (Clerf, 1952). Also at that time there were discussions about applying 'hits' on different areas of the back, via different means (hand, pillows) but these were discouraged as causing more harm depending on where the FB was located (Gross, 1854). This controversy on the use of back blows has proven ongoing, with the Red Cross teaching back blows for choking from the 1930s-1970s, withdrawing their recommendation from their textbook from 1973-78, and then reinstating them in their teaching in 1976 (Hoffman, 1982; Montoya, 1986).

Cardiopulmonary resuscitation (CPR), now a part of the full choking first aid procedure, had its origins in the early 1890s when the first successful closed chest cardiac massage took place (DeBard, 1980). The American Heart Association took the lead, beginning a program for physicians in this closed chest cardiac resuscitation, which lead to training of the general public after

¹⁶ Mouth to mouth resuscitation was an innovation of the 1700s to aid drowning victims, By the mid-20th century it had been adopted to revive unresponsive victims (American Heart Association, 2017).

CPR was formally endorsed by the association in 1963 (coincidentally the same year as Haugen's article) (American Heart Association, 2017).

Identifying risk factors

What marks the studies of Haugen and others appearing in the mid-20th century was that, faced with the ongoing problems of choking presented above, and with limited aid responses available to potentially offset them, focus was shifting to prevention. Reporting on his autopsy findings for the cases in question at the Broward County Medical Examiner's Office, and seemingly with his sensibilities offended, Haugen commented:

The size of the obstructing food was atrocious in all cases and abominable in one...illustrating the tremendous bulk of food that can be placed in the mouth. The obvious lack of ordinary table manners is of prime importance in these accidental deaths (Haugen, 1963, pp. 142-143).

Haugen was considering not only the physiological effects of choking but what he considered to be the most common circumstances and causal factors that lead to a foreign body airway obstruction. "Acute alcoholism, poor teeth, and atrocious table manners are considered to be the precipitating factors" (Haugen, 1963, p. 143). Haugen was highlighting environmental circumstances (a restaurant with liberal amounts of alcohol present in which people indulged) and personal (physiological and behavioural) factors (lack of good dentition and poor table manners) contributing to a choking event. The 'cure' of foreign bodies blocking the airways was broadening to consider physiological factors including the inability to effectively masticate food due to lack of teeth, the potential central nervous effects of alcohol on the swallowing mechanism and judgement, and behavioural factors such as how we conduct ourselves.

Haugen however, was commenting on a very small number of cases; choking events with the common link of having occurred at a restaurant. Haugen even coined the phrase 'café coronary' to draw attention to these cases, a term that would be used for many years to characterise choking,

highlighting the obstruction on food, the likely environment, and the common misdiagnosis of an unrelated coronary event (Haugen, 1963). Haugen's insights were essentially highlighting choking in the general population, and although not articulated outright there was also in his findings an important implicit shift in how choking was viewed in terms of control over or implied responsibility for the event.

The hapless victim of choking, while having limited control once a choking event occurred, did potentially by Haugen's construction have some control over whether the event occurred in the first place, such as moderating alcohol consumption or chewing their food. Changing 'atrocious table manners' in order to 'cure' choking therefore introduced possible issues in the choking reality around who had control of and responsibility for mitigating risk factors once identified. These issues would become even more complex as choking studies broadened, both to acknowledge the increased risk of those with particular medical conditions and to consider the involvement of professional and lay carers.

The 1970s: Café coronary, risk factors beyond the café

The circumstances around and poor identification of choking highlighted by Haugen would continue to exist as contributors to choking risk (Berzlanovich, Muhm, Sim, & Bauer, 1999; Mittleman & Wetli, 1982), but the 'fatal café coronary', the phrase used by Haugen to describe fatal food obstructions of the airway, was not restricted to the café scene, as other research would show (Irwin, Ashba, Braman, Lee, & Corrao, 1977; Mittleman & Wetli, 1982).

In 1977, a group of doctors lead by Richard Irwin, wishing to highlight how little had been written on choking in hospitalised patients, reported in the general choking literature¹⁷ on a study they conducted into food asphyxiation in 14 patients in an institution for chronic disease, thus moving the focus from the risks of the social environment of a restaurant to those of a medical facility (Irwin et al., 1977). Like Haugen only focusing on a small number of

¹⁷ Choking in the mental health literature had started to explore factors associated with institutionalisation.

cases, Irwin's team essentially reinforced Haugen's findings, citing advanced age (8 of the choking residents were over 70) and poor or absent (Carl & Johnson, 2008) dentition as predisposing factors. Of the 14 patients who died, 10 did so during a meal or shortly after, and yet only once was asphyxiation considered the cause of death (acute myocardial infarction was erroneously diagnosed as the cause of death for most subjects, similarly to Haugen's work). Fourteen years on from Haugen's study, recognising a choking event and its causal relationship with death was still a problem.

What was of particular note in Irwin's study was that he reported the patients showed little forewarning of aspiration¹⁸, but went on to state that three of the patients had been reported by nursing staff to have had previous choking instances, two of whom on autopsy showed evidence of a history of aspiration (Irwin et al., 1977). Such findings were perhaps indicative of possible, unidentified, underlying swallowing problems. Indeed, dysphagia would come to be considered a significant and fundamental contributing factor to choking risk, as larger forensic studies began to identify the high statistical incidence of medical conditions associated with swallowing in the data (Berzlanovich et al., 2005; Mittleman & Wetli, 1982).

Predisposing factors for choking at this time however, were still few in number. The shift in setting from restaurant to hospital may have eliminated the risk of alcohol as a contributing factor for choking, but introduced the new factor of sedation; 10 of the 14 patients studied were on sedatives at the time of fatality (Irwin et al., 1977). The idea that medication and its side effects might have a contributing role in choking had been gaining traction in the mental health literature.

New psychotropic drugs introduced in the late 1950s to treat those with psychiatric illnesses were coming under scrutiny as a risk factor for the high incidence of choking in the mentally ill, resulting from the significant disturbances in swallowing function thought to be caused by these drugs (Von Brauchitsch & May, 1968). These concerns continued to be debated

¹⁸ Inhalation of foreign matter.

into the late 20th century, with some studies indicating a direct link between certain medications, dysphagia, and choking, and others suggesting risk was dependent on multiple variables being present, such as medication, high dosing, and age (Craig & Richardson, 1982; Hsieh, Bhatia, Andersen, & Cheng, 1986; Hwang et al., 2010).¹⁹

Returning to Irwin et al., despite essentially reinforcing factors already identified in Haugen's earlier work and the mental health literature, Irwin and colleagues' study is of note in that it marks the advent of the dual approach to choking management that was appearing in the late 1970s; the desire to identify and control risk factors along with the use of the new 'first aid' techniques that were beginning to be promoted. Articulating this twin approach, Irwin's team concluded the key factors for choking in hospital patients were old age, poor dentition and sedation, and recommended the judicious use of sedation and appropriate food for those lacking teeth. They also called for doctors, in addition to CPR, to be trained in the "...simple methods of manually removing inhaled food as well as the Heimlich manoeuvre" (Irwin et al., 1977, p. 2745).

The construction of choking can be seen to have radically changed and expanded from the Renaissance; from a visitation of God, to the recognition and perhaps controllable consequence of a foreign object blocking the

¹⁹ It is now acknowledged that medications used to mitigate the symptoms of mental illness and indeed other conditions may have side effects that create or worsen dysphagia, by disturbing motor function, lubrication of the swallowing tract, and gastrointestinal motility, through a variety of physiological mechanisms (Carl & Johnson, 2008; Fioritti et al., 1997). Anticonvulsant, antipsychotic and anti-anxiety drugs that affect the central nervous system are often used to assist people with mental health issues. These drugs can impair sensation in the mouth and throat area, disturb saliva production, suppress swallow function and reflexes, produce extraneous muscle movement, muscle weakness, or paralysis, and reduce a person's level of arousal leading to poor attention when eating (Carl & Johnson, 2008; Fioritti et al., 1997; Von Brauchitsch & May, 1968). A direct association between medications and their different physiological mechanisms and choking remains elusive however, compounded by the presence of underlying mechanical swallowing difficulties and disturbed eating behaviours specifically associated with the mental illness (de Nesnera & Folks, 2010; Ruschena et al., 2003; Von Brauchitsch & May, 1968) or other medical conditions.

airway. The works of Haugen, Irwin and others were introducing the idea that there were things beyond the Divine that could act as harbingers of the possibility of death in the choking context.

Maintaining alignment with the reductionist and mechanistic view of disease and health, medical researchers of the 20th century were implying that if factors that could disturb the human machine's ability to function could be identified then they could be eliminated or controlled. Identifying and dealing with the problem when it occurred (diagnosis and intervention) now expanded to identifying and dealing with 'the possibility' that the problem might occur and the need to offset that possibility.

The 1980s: More risk factors

In 1982, nearly 20 years after Haugen's work, Mittleman and Wetli published an often-cited forensic study of 141 choking fatalities (Mittleman & Wetli, 1982). Spanning 20 years of data (1960 – 1979, thus overlapping in time both Haugen's and Irwin's studies), this work sought to present a comprehensive overview of demographic features and other predisposing factors for fatal food asphyxia from cases brought to the attention of the Dade County (US) medical examiner's office. Its goal mirrors Gross's intention of 130 years previously: 'to uncover the facts of choking', only this time not from a diagnostic and interventionist perspective but from a preventative viewpoint. Gross's focus on the physiological aspects of choking had shifted to Mittleman and Wetli's broader view that encompassed the circumstances that might place an individual more at risk of choking.

Mittleman and Wetli's study focused specifically on food obstructions, eliminating from analysis cases of catastrophic aspiration of vomitus and non-food related foreign body airway obstructions. Surprisingly, only 7% of their cases were children, indicating that adults seemed at higher risk of food obstruction (Mittleman & Wetli, 1982). This possibility was confirmed in later studies (Hoffman, 1982; Soroudi et al., 2007), with food-related fatal obstructions in people over 65 years estimated as being seven times greater

than those of children under 4 years, the previously thought highest risk group (Kramarow et al., 2014).

The reinforcement and identification of more risk factors

Mittleman and Wetli's much larger study reinforced the work of their predecessors and smaller studies, but expanded the scope of predisposing factors. Their findings reinforced alcohol and drugs (sedatives and hypnotic drugs, particularly barbiturates) as potentially significant factors due to their high presence in the cases studied, indicating that the high incidence of choking in those of advanced age may be due to alcohol being their recreational drug of choice, and echoing Haugen's view. This rationale however would be over-shadowed in later years by the association of advanced age with the predisposing factors of neurological disorders and presbyphagia (Cleary & Hopper, 2010; Ney et al., 2009; Shemansky, 1991).

These researchers (Mittleman & Wetli, 1982) also concluded that poor dentition was a recurring feature in those who fatally choked. They identified additional factors however, noting the frequent occurrence of certain conditions such as cerebrovascular disease, mental retardation²⁰, and Parkinson's disease. Based on the high incidence of those with Parkinson's disease in their study, they proposed that conditions affecting motor function and mental functioning might be implicated as other predisposing factors. They recommended attention be directed to such 'natural diseases' in future studies. Other than chewing difficulties, they did not specifically highlight dysphagia as an underlying factor which might be connected to natural diseases and their potential for choking risk.

Interest in studying specific clinical groups was developing, with particular acknowledgement in the mental health literature that certain conditions attracted a higher choking incidence than the general population (Craig & Richardson, 1982). Mittleman and Wetli (1982) estimated choking fatality in the general population to be 0.66 per 100,000. This estimate has varied over

²⁰ Intellectual disability or learning disability would be the terminology more likely to be used in the early 21st century.

the years with an estimated range of 0.1 to 2 per 100,000 per year, with 2 per 100,000 the often-quoted estimate²¹ (Berzlanovich et al., 2005; Fioritti et al., 1997; Wick et al., 2005). Medical researchers Craig and Richardson (1982), based on their 9-year study in the mental health area at the time, initially estimated that psychiatric patients were 100 times more likely to choke than those of the general population. Over the life of their study this incidence was reduced, they believed, due to changes in medication regimens and the introduction of training in the Heimlich manoeuvre²² (Craig & Richardson, 1982). Mental illness continues to be highly represented in choking statistics however, with people with schizophrenia reported to be 30 times more at risk of choking fatality than the general public (de Nesnera & Folks, 2010; Warner, 2004).

Mittleman and Wetli's (1982) general findings also expanded the notion of where adults were more likely to choke. Institutionalised adults were more likely to fatally choke in nursing homes and mental institutions²³, while 'free roaming'²⁴ adults were more likely to choke at home, followed by a restaurant or at a friend's home. This was a particularly important finding, as it directed attention to who might be present at a choking event and, with the advent of the new first aid techniques (CPR and the Heimlich manoeuvre had been gaining traction in the 1970s and 80s), the range of who might need these skills.

They also in collecting their data identified what people choked on (Mittleman & Wetli, 1982). Their findings in this area were of particular note in that they opened up an area of exploration which had not been previously focused on in depth and which would have far reaching consequences for how choking risk would be managed in the future. Haugen's work (1963) had implicated meat as a prime obstructing food, directly connecting it with poor dentition

²¹ It is believed this may be an underestimation given continued problems with choking deaths being attributed to other causes.

²² More conservative numbers for incidence have been projected in recent studies (Ruschena et al., 2003; Yim & Chong, 2009).

²³ As terms and societal norms change it is difficult to know whether a 'mental institution' in the 1980s equated to the mental health facilities of today and whether they would have provided care for people with mental illness or intellectual disability or both.

²⁴ Descriptive phrase used by Mittleman and Wetli (1982) to indicate non-institutionalised adults.

and an inability to 'process' the food (break it up into small pieces in the oral cavity) due to lack of appropriate mastication. Irwin's team had made no comment on the type of food their subjects choked on, but in their recommendations advocated appropriate food (no large chunks or portions of food) for those lacking teeth (Irwin et al., 1977). Mittleman and Wetli (1982) however went further. Their findings indicated a range of foods that adults obstructed on, which included meat (approximately three quarters of the free ranging adults in the study choked on meat) but also foods the researchers described as 'soft and loosely textured' (institutionalised adults tended to choke on these kinds of food). What Mittleman and Wetli showed was that while meat was often the obstructing food it was not the only one, as importantly a whole range of types and textures of food could block the air-passages.

Future studies would document an increasing list of different foods which people fatally choked on, with one study listing 41 different types of such food, of single and multiple textures (Dolkas et al., 2007), leaving no type of food or texture innocent of the capacity to obstruct. The significance of Mittleman and Wetli's findings on the types of food people fatally choked on was twofold. It reinforced that while poor dentition was probably a significant contributing factor in choking it was unlikely to be the only one, and compensating for it by modifying meat or providing soft textures was not a guaranteed solution to the multi-factorial nature of choking.

Mittleman and Wetli's study also highlighted a new risk connected with the texture of food and prevention of harm when a choking event did occur. The 'soft and loosely textured food' was noted to be less amenable to choking first aid (such as the use of the Heimlich manoeuvre and 'plastic forceps' to dislodge or remove obstructions). The authors concluded "...serious consideration should be given to different rescue techniques in light of the different foods that may be encountered" (Mittleman & Wetli, 1982, p. 1287), and further advised that "[f]uture development of the new lifesaving methods should include consideration of asphyxiation from soft foods that cannot be cleared with a grasping device or the abdominal thrust manoeuvre"

(Mittleman & Wetli, 1982, p. 1288). What these different methods should or could be was not forthcoming.

Mittleman and Wetli summed up the optimism of the new paradigm of prevention: “As in other areas of medicine, prevention is easier than cure once the predisposing factors have been identified” (Mittleman & Wetli, 1982, p. 1287).

The next 30 years: An explosion of risk factors

Over the next 30 years clinical research in choking would wax and wane, but the search for risk factors and recommendations to control them would continue. However, forensic interest in choking fatalities would be reignited at the beginning of the 21st century.

International research teams continuing the forensic tradition of retrospective analysis of coroners' reports would publish a number of studies in the first decade of this century. These studies, covering cases from the mid-1980s to 2004, further illuminated the risk factors of choking (Berzlanovich et al., 2005; Berzlanovich et al., 1999; Dolkas et al., 2007; Wick et al., 2005).

Exploring the salient characteristics outlined in Mittleman and Wetli's 1982 study, these international researchers explored choking in 3 different countries: Australia [South Australia] 43 adult cases (Wick et al., 2005); US [San Diego County] 131 adult cases (Dolkas et al., 2007); and Austria [Vienna] 189 adult cases (Berzlanovich et al., 1999) – all adding further weight to the identified predisposing factors for choking and providing new insights. Simultaneously, the work of other researchers, particularly those focusing on particular populations had begun, and continued to develop the choking picture and contribute to general forensic studies (Aldridge & Taylor, 2012; Berzlanovich et al., 2005; Cleary & Hopper, 2010; Ekberg & Feinberg, 1992; Finestone et al., 1998; Fioritti et al., 1997; Samuels & Chadwick, 2006; Thacker et al., 2008).

Drawing on the increasing number of cases being analysed across multiple studies, previously identified risk factors continued to be represented and

new ones suggested. Poor dentition, advanced age (particularly those over 70), residency (including those institutionalised) and eating location, and the presence of alcohol and drugs, were all highly represented as possible predisposing factors. Mittleman and Wetli had recommended in their 1982 paper that future research should consider medical conditions that might predispose someone to choking. Forensic studies in the first decade of the 21st century confirmed that over 50% of adults who fatally choked on foreign bodies had some form of neurological disorder such as dementia, mental illness, stroke or learning disability, or had an anatomical problem which disrupted swallowing (Berzlanovich et al., 2005; Berzlanovich et al., 1999; Dolkas et al., 2007; Wick et al., 2005). Wu and colleagues, studying the association between chronic diseases and choking deaths between 2009-2013 using coroner's reports, found seven chronic diseases showing significance for association with food and non-food choking. These diseases in order of statistical significance were schizophrenia, Parkinson's disease, laryngeal cancer, Alzheimer's disease, oral cancer, stroke, and mood (affective) disorders (Wu, Sung, Cheng, & Lu, 2015).

As studies went on to identify which medical conditions had the strongest association with choking, pockets of research began occurring on particular illnesses encompassing fatal and non-fatal studies at a case study and group level (Archibald & Newman, 2009; Ekberg & Feinberg, 1992; Finestone et al., 1998; Goh et al., 2016; Hadjikoutis et al., 2000; Hollins, Attard, von Fraunhofer, McGuigan, & Sedgwick, 1998). Associated dysphagia and/or cognitive problems were highly represented among the medical conditions being focused on.

Dysphagia as a fundamental risk for choking

Over time, dysphagia had come to the fore as a fundamental risk factor for choking, whether caused by a medical condition, medication effects, or normal ageing (presbyphagia) (Cleary & Hopper, 2010; Ekberg & Feinberg, 1992; Feinberg & Ekberg, 1990; Finestone et al., 1998; Hadjikoutis et al., 2000). Cognitive problems that influenced behaviour around eating, such as

food cramming (placing large amounts of food in the mouth), excessive speed of eating, and consuming non-food items were also being established as high risk factors, compromising even normal swallowing mechanics (de Nesnera & Folks, 2010; Samuels & Chadwick, 2006; Von Brauchitsch & May, 1968).

The two fundamental risk factors of dysphagia and impaired cognition brought choking into sharp focus as a clinical concern. Members of the general population did fatally choke for the reasons Haugen had articulated in the 1960s, but adults with medical conditions associated with dysphagia or cognitive problems were at much higher risk for such fatality, and for potentially different reasons. A focus on these arguably more vulnerable adults led to an explosion of identification of possible predisposing and related factors for both choking risk and associated fatality.

Appendix 1 provides a snapshot of the breadth and number of factors being attributed to choking susceptibility. Some of these are expressed in broad brush strokes such as 'neurological disorders' or 'cognitive problems' (Berzlanovich et al., 2005), while others are more specific such as 'poor dentition' or 'food gorging' (Appelbaum, Bazemore, Tonkonogy, Ananth, & Shull, 1992; Ekberg & Feinberg, 1992; Yim & Chong, 2009). Some of the factors contributing to choking are determined by incidence numbers (for example, fourth leading cause of death in those over 85 (Cleary & Hopper, 2010)), others by extrapolation from observation in clinical settings (such as eating quickly because of desirable activities scheduled for after meals (Guthrie & Roddam, 2011)), still other attributed factors seem born of 'common sense' logic (the larger the piece of food the more likely it is to block a narrow airway (Finestone et al., 1998)), and yet other less immediately obvious contributors such as illiteracy, from specific studies looking at predictive variables (Thacker et al., 2008). What was becoming clear as new factors were uncovered or speculated about was the profound complexity of the reality of choking.

The 'truth' of choking was that it was multi-factorial and multi-layered.

Advanced age had initially been identified as a significant factor, but as knowledge increased other variables emerged to cloud the picture of a definitive link. Was the association of advanced age with choking due to alcohol being the recreational drug of choice for this age group; normal age-related changes to the swallow reflex; cognitive problems caused by medical conditions more likely with age such as dementia; the side effects of medication used to treat chronic illness; or living in supported care and being fed by multiple carers of varying skill? Each possible factor seemed to lead to other factors, creating a labyrinth of risks, where the degree of risk of each factor was far from clear.

Mittleman and Wetli's optimistic view that "...prevention is easier than cure once the predisposing factors have been identified" was with more research becoming buried under an ever-increasing number of single and interrelated factors, the control of which was far from assured (Mittleman & Wetli, 1982, p. 1287). To further complicate matters, prevention itself had two aspects: the prevention of a choking event occurring and then the prevention of death if choking did occur. Thus identifying factors that could precipitate a choking event and identifying factors that could stop the provision of aid when an event occurred were paramount.

During the 20th century, management of choking became focused on both intervention and prevention. In pursuing a prevention focus a presumption was made that there were factors that could precipitate a choking fatality and that these factors could be reduced or controlled. One of the most significant consequences of this new focus was the shift it would create in who would assume responsibility (by choice or default) for the reduction or control of all the risk factors being identified.

The overseers of choking

The introduction of the new paradigm of prevention as an attempt to manage choking fatalities created a necessary shift in and shared dominion over the area of choking. God had given way to the men and later women of medical

science with their focus on intervention, but prevention meant responsibility, initially at least, would lie predominantly with whoever was present leading up to and at the time of an airway obstruction. Such 'response/ability' would be expressed either through the ability to reduce or eliminate a choking event occurring or the ability to respond in the time-critical space when the immediately life-threatening event took place (Pearn, 2000).

For the general population, risk factors such as the consumption of a large amount of alcohol or eating too fast situated predisposing risk factors and their potential control very temporally close to an event, with their control resting with the person themselves. For vulnerable at-risk adults (such as those with dysphagia or cognitive problems) more complex risk factors could be present, creating an ongoing underlying state of risk, which others may have involvement in controlling.

The larger studies on choking had identified that while people did choke in cafés, they were more likely to choke at home, in medical/care institutions such as nursing homes or mental health facilities, or at private social gatherings (Dolkas et al., 2007; Mittleman & Wetli, 1982). Thus who may or may not be present was diverse, including family, friends, health care professionals and workers, the general public, or only the victim.

The need to address predisposing factors and effectively respond to the immediacy of harm if an event occurred appeared to be supported by two phenomena evolving in the later part of the 20th century; the development of a profession focused on dysphagia care for those particularly at risk and the global explosion in first aid training (Miller & Groher, 1993; Pearn, 2000).

Focus on dysphagia

In the 1980s a profession was evolving that appeared logically placed to be pivotal in choking prevention because of its increasing involvement in the assessment, diagnosis, treatment, and management of dysphagia.

Historically, the Speech Pathology profession had been concerned with the diagnosis and treatment of communication (speech or language) disorders,

which included the identification of factors which either increased or decreased the handicap of these disorders. The diagnosis and management of speech disorders in particular meant this profession's knowledge base focused on oral motor dysfunction; dysfunction that impacted on the muscles involved in speech, voice, and swallowing. Many of their clients such as children with cerebral palsy had both communication and swallowing problems (Miller & Groher, 1993; Speech Pathology Australia, 2017).

Individual circumstances lead some speech pathologists to become involved in both aspects of impairment as early as the 1930s (Miller & Groher, 1993). Ruth Porteous however, one of the first speech pathologists to graduate in Australia, reflecting on the history of the profession, recalled that in the 1950s when she graduated they had never heard of dysphagia (Porteous, 2003). It was not until the 1960s in America that speech pathologists George Larsen and later Jeri Logemann set in motion the groundwork which would later lead to speech pathologists in America and Australia in the 1980s being acknowledged as the formal overseers of dysphagia care (Miller & Groher, 1993; Speech Pathology Australia, 2014).

Perhaps the first documented involvement of the relationship between speech pathologists, dysphagia and choking was an early experiment/treatment attempt by George Larsen. Larsen, working in a hospital setting in the early 1960s, had been challenged and encouraged by physician mentors to expand his knowledge and practice to include dysphagia assessment and treatment (Miller & Groher, 1993). Rising to the challenge and after much self-study and mentorship Larson, faced with a patient who could not initiate a swallow (despite attempts at various stimuli such as verbal cuing), resorted to a more powerful physiological stimulus by applying an "...electrical current to the patient's thyroid notch²⁵..." stimulating the initiation and return of normal swallowing function (Miller & Groher, 1993, p. 181).

The fledgling speech pathologists observing him at the time reported that:

²⁵ Externally, V shaped indentation immediately above the larynx (voice box, Adam's apple).

Our collective elation and surprise that ‘treatment’ could be so simple and successful was quickly dampened when Larsen warned that it could be dangerous to use such a technique with all patients because of the potential life-threatening consequences of laryngo-spasm²⁶ (Miller & Groher, 1993, p. 181).

Essentially, the choking of the patient by causing the vocal cords to spasm and close, blocking the trachea and airflow! In his earliest publications on dysphagia, Larsen commented on the need for appropriate head and neck posture to reduce choking risk and advocated for patient education on what happens when a choking event occurs. He also advocated for a team approach to dysphagia care and trained carers to assist with feeding (Miller & Groher, 1993). Choking was very much seen as having a direct relationship with dysphagia and being one of its life-threatening risks.

Another early pioneer in the area was Jeri Logemann. Logemann, in her post-doctoral work in the late 1960s, teamed up with a radiologist (Dr B.J. Hill) to examine muscle movement involved in speech, voice, and swallowing through various innovative radiographic techniques. Asked to develop a safe and objective way of assessing swallowing function in people with Parkinson’s disease who were being weaned off old medications in order to try the new drug levodopa, she developed the modified barium²⁷ swallow. The modified barium swallow was a radiological technique which provided a moving x-ray of what was happening in the oro-pharynx when someone swallowed (prior to this a ‘barium swallow’ had been used only to view what happened in the oesophagus when barium in fluid form was ingested). This new diagnostic innovation contributed to the understanding of basic swallowing physiology, with Logemann using the modified barium swallow not only to assess swallowing but to test the efficacy of possible therapy techniques such as the impact of changing food or fluid texture (Miller & Groher, 1993).

²⁶ Vocal cord spasm which prevents air-moving through the air passage.

²⁷ Barium is a substance that shows up on x-ray. Logemann imbedded the barium in food and fluids - ‘the cookie swallow test’ - to be able to view the different phases of swallowing.

Originally mentored by physicians, working in health facilities, and drawing on the medical fields of anatomy, physiology and neurology, the speech pathology profession built up a knowledge base of scientific inquiry focused on the physiology of swallowing and application of adaptive treatment and strategies (Miller & Groher, 1993). Dysphagia care was naturally aligned with the biomedical model. A profession which had for most of its history been concerned with the 'quality of life' aspects of remediating communication and learning disabilities and understanding the factors that created handicap, had expanded to include swallowing problems. The 1980s would see the profession playing an increasingly medically orientated role in the treatment and management of swallowing disorders.

By the 1990s speech pathology would be established as occupying a leading role in dysphagia care (Speech Pathology Australia, 2014). Choking, along with aspiration, malnutrition and dehydration were considered the primary risks of dysphagia (Speech Pathology Australia, 2014). Speech pathologists, owing to their knowledge base and involvement with all the medical conditions associated with dysphagia and choking, were well situated to play a significant part in identifying an at-risk adult's choking risk and controlling for it. By promoting the management of dysphagia through education, treatment when possible, and the use of compensatory strategies such as verbal prompting, correct posture for eating, skilled feeding assistance, texture modified diets or non-oral feeding when indicated, the risk of choking as a consequence would be reduced or eliminated.

Initially the study of choking had focused on studying the physiology of choking; identifying the location and consequent effects of different types of obstructions. This refinement of knowledge spearheaded different attempts to intervene and remove the obstruction. When attempts at intervention proved promising but did not resolve the fatality in many situations, the focus moved to prevention and a desire to identify risk factors and control them. However if attempts to identify or overcome risk factors failed and choking occurred, preventing harm through intervention once again became the priority, and

new innovations in the development of choking first aid in the 20th century would be there as a backup.

First Aid

Launched by the innovations of the 1960s and 70s, by the 1980s and 90s the new first aid techniques of CPR and the Heimlich manoeuvre were being consolidated into public education programmes. First aid or basic life support (BLS) "...the drills and skills which the bare-handed bystander can utilize to maintain life" (Pearn, 2000, p. 3), had expanded from the simple techniques that had been taught by the fledging first aid organisations of the late 1800s and first half of the 20th century (Pearn, 1998). A fusion of the new techniques lead to a formal procedure for choking first aid, which currently in Australia includes back blows, chest thrust (the successor to the Heimlich manoeuvre) and if required CPR (St John Ambulance Australia, 2013). Spearheaded by CPR, first aid training for the lay public has gone global; by 2000 Australia had one of the best national figures for BLS training (Pearn, 2000). Prior to the 1960s, complete obstruction of the airway meant death, unless medical personnel were present and often even then (Eisenburger & Safar, 1999; Pearn, 2000); choking first aid held out the promise of changing that.

Armed with a general public trained in choking first aid and a profession primed to support those in clinical populations most at risk of choking, cure through prevention for a fleeting moment seemed possible. The 'reality of choking' was not one of fatality; prevention and if necessary intervention (basic or advanced aid) together could fix the 'human machine', or so it was hoped.

SECTION 3: THE CONTEMPORARY SPACE:

CHALLENGES AND FURTHER TRUTH SEEKING

The need for a new perspective

Just over 250 years since the first research on foreign bodies in the airways was presented by Dr Louis and 150 years since the seminal work of Gross, much has been learnt about choking. Yet despite truth-seeking efforts that have led to enhanced knowledge and innovations in intervention and prevention, choking fatalities continue. People observing a choking event still often fail to recognise what they are witnessing, and the incidence of choking deaths – which itself has never been clear because of misdiagnosis and inclusion criteria – cannot with any confidence be argued to have been reduced overall, although some improvements have been reported in the mental health area (Berzlanovich et al., 2005; Berzlanovich et al., 1999; Craig & Richardson, 1982; Mittleman & Wetli, 1982; Wick et al., 2005). Commenting on the United States situation, Michael Sayre notes: “Despite widespread education on the use of the Heimlich manoeuvre and other techniques for treatment of acute airway obstruction, the death rate remains stable” (Sayre, 2005, p. 112).

Far from finding a biomedical choking reality that could be prevented, the reality of choking seems to defy attempts to control it. Historically, choking has never been free from a relationship with social phenomena; poor dentition, a risk factor commonly identified over the years (Haugen, 1963), potentially has its roots in broader social issues such as education, access to dental care, and economics related to food choices and dental services. However the social context as such has not been a particular focus, outside of identifying and listing some of its elements as risk factors needing control. Appendix 1 as previously noted provides an insight into the factors thought to be associated with choking risk in the literature, some of which, such as drinking excessive alcohol, poor health care, stealing food and eating in

secret (Appelbaum et al., 1992; Thacker et al., 2008; Warner, 2004; Wick et al., 2005), are potentially related to social phenomena.

Teasing out possible influences in the contemporary space

In the contemporary space of choking and its management, interest in social phenomena remains connected to the primary aims of identification and control of risk factors. While there is a dearth of literature specifically aimed at exploring the social context of choking in its own right, there are non-fatal studies that nevertheless make a valuable contribution to illuminating some of the social phenomena around choking. These studies often use interviewing as a method to illuminate specific aspects relevant to dysphagia and choking, such as how people feel about it, the changes they feel forced to make as a consequence, and the challenges of meeting the demands choking presents (Balandin et al., 2009; Chadwick, Jolliffe, Goldbart, & Burton, 2006; Guthrie & Roddam, 2011; Guthrie & Stansfield, 2017). This study aims to reinforce and add to this work.

Adding to insights gleaned from individual studies on specific topics, there is in the area of dysphagia – of which choking is a part – a growing interest in considering broader, social aspects that have implications for care. As part of this shift, consideration of the effect of dysphagia on quality of life (QoL) has become an increasing focus of research. Five aspects of dysphagia have been identified as being relevant to the investigation of its impact on QoL: identifying the problem; the physical experience; the emotions evoked by it; the impact of dysphagia on social engagement; and the nature of its treatments (Watt & Whyte, 2003).

The effects of dysphagia are many, such as: it not being taken seriously and concomitant feelings of lack of respect; social isolation; depression, low self-esteem and anxiety; pain and discomfort; loss of pleasure in eating and its associated symbolic meaning; concern and fear about choking; embarrassment and loss of dignity; negative effects on relationships; and the aversion to tube feeding and texture modified food used to treat it. These have all been identified as being related to and reducing QoL in at-risk adults

(Chen, Golub, Hapner, & Johns, 2009; Ekberg, Hamdy, Woisard, Wuttge–Hannig, & Ortega, 2002; Keller, Chambers, Niezgoda, & Duizer, 2012; Vogel, Brown, Folker, Corben, & Delatycki, 2014; Watt & Whyte, 2003). A desire to explore the broader social implications of dysphagia has included the development of the SWAL-QOL assessment tool, which focuses specifically on dysphagia and perceptions of QoL, and includes an acknowledgement of anxiety and fear around choking as an item of note (McHorney et al., 2000); other QoL assessment tools have also been utilised in this area of more socially-focused research (Ekberg et al., 2002; Watt & Whyte, 2003). The possible effects on the QoL of informal carers has also been studied by researchers such as Givens and colleagues, who in the course of their research noted the high level of distress felt by carers when their loved one with dementia experienced choking episodes (Givens, Prigerson, Jones, & Mitchell, 2011).

In the contemporary space of general dysphagia literature, there is a tension in regard to choking and how its relationship to QoL is perceived. While a definitive definition of QoL is difficult to come by, Watt and Whyte (2003, p.184) suggest that “...there is growing consensus that it is the subjective evaluation of life as a whole, encompassing the multiple dimensions of physical, functional and psychosocial well being”. Historically, the choking literature has primarily focused on the physical. There is a tension however between the physical and the social in the consideration of choking from a quality of life perspective, that is beginning to be identified and explored in commentaries about refusal of texture modified food, which is a major preventative treatment used for choking (Kaizer, Spiridigliozzi, & Hunt, 2012; Kenny, 2015).

Multiple commentators have discussed the heightened fear of eating associated with choking risk or events for at-risk adults (Ekberg et al., 2002; Hung & Chaudhury, 2011; Verdonschot, Baijens, Serroyen, Leue, & Kremer, 2013) and the often accompanying distress to informal and formal carers (Givens et al., 2011; Vogel et al., 2014). Fear is the one social phenomenon associated with choking that is often showcased. The lack of specificity of

QoL definitions like Watt and Whyte's (2003) potentially creates a space where both subjectively and objectively, when an issue like choking generates such fear, enhanced QoL will automatically be conceptually linked with choking reduction. Thus its treatment approach, in this case prevention, potentially becomes conceptually indistinguishable from promoting QoL, and by extension prevention becomes equated with physical, functional, psychological and social wellbeing. In essence, such an approach reflects and reinforces a pervasive belief that faced with choking everyone would chose to do whatever it takes to prevent it. For some this will be the belief, but not for others. More expanded definitions of QoL are being offered that tease out more of the social issues that may impact on how people view risk and prevention strategies that may be restrictive in both dysphagia and choking care. Kaiser and colleagues represent QoL as referring:

...to how the individual perceives their life in the framework of their own culture and ideals and the way in which they live as related to their goals, expectations of life and standards of living, quality of life does not refer only to physical health, but also psychological health, social relationships and environment combined with the individual's underlying value system (Kaizer et al., 2012, p. 2448).

This more detailed definition suggests that even with the possibility of choking and the anxiety that may accompany it, there may be other concerns which are considered to be as or more important by at-risk adults. Thus a conceptual space in the area of dysphagia care and by default choking care has been created in the contemporary landscape for discussing the tension between a desire to reduce risk and a desire to maintain or pursue aspects of life that give it meaning (Kaizer et al., 2012; Kenny, 2015). The opening of such a conceptual space and the promotion of more nuanced definitions of QoL also create the challenge of considering that QoL may not only be relevant to the at-risk adult. Aspects of choking and its care may also impact on the QoL of informal and formal carers if elements of the social context of choking challenge the ideals, values, relationships and environments of these individuals (Kenny, 2015).

Whether the focus is on reducing risk or promoting QoL, the social context of choking matters in illuminating what is important to at-risk adults and their carers. It is also important to understand the broader social context that will both create and influence how those intimately involved in choking experience it.

Contemporary 'hot spots' in choking: First aid and texture modified diets

As previously stated, this literature review was performed at the end of analysis of the study data, in keeping with the methodology of classic grounded theory (Glaser & Strauss, 1967). The first two sections of this chapter have illuminated the theory of prevention – the prevention of choking events and the prevention of harm if events do occur – thus showcasing the theory which underpins the current approach to choking and clinical care. While challenging, compiling a historical perspective is relatively easy, in that standing at a viewing point from which hindsight is possible, it is easier with all the information before you to identify the general themes, the key debates, the successes or failures of thought and practice innovation. The telling of history allows a pruning of the false starts and hiccups that likely characterised the developments uncovered, to present what appears to be a linear, logical and coherent reaching of accepted knowledge. Once one enters the contemporary space however, it is more difficult to pin point what areas one can feel confident about, as the conceptual field is in flux, with new ideas and innovations appearing and disappearing, and controversies arising, evolving, resolving or expanding.

On reviewing the literature post analysis of the study data and in light of the history already presented, two particular 'hot spots' – areas undergoing changes in conceptualisation – are evident in the contemporary space, which are germane to the social context of choking. These two areas are 'choking first aid' and 'the use of texture modified diets'. Both areas represent key approaches used in the prevention arsenal to avoid choking risk and fatality. The current state of development in these areas however is both pertinent as

a backdrop to the study data and also suggestive of where the theory emerging from this study might sit in the contemporary space. To that end, some of the main issues in choking first aid and texture modified diets will be briefly outlined.

Failing to prevent death: Choking and the current understanding of first aid

John Pearn, Surgeon General of the Australian Defence Force, views basic life support (which includes choking first aid as a part of clearing the airway) and its CPR component specifically as being ‘...the responsibility of all, irrespective of age, occupation, profession or social status’ (Pearn, 2000, p. 3). The Australian Resuscitation Council states in its guidelines: ‘A Foreign Body Airway Obstruction (FBAO) is a life-threatening emergency. Chest thrusts or back blows are effective for relieving FBAO in conscious adults and children’ (Carey, 2014, p. 5). Such declarations paint a rosy picture, where everyone in the community is trained in first aid and every obstruction removed by the application of that aid. However the choking reality belies the truth and reasonableness of such assumptions.

The techniques of chest thrusts, back blows or other current techniques used as part of choking first aid are hardly guarantees of success. In 2013, Anthony Handley, editor of *Resuscitation*, the official journal of the European Resuscitation Council, wrote an editorial entitled: ‘At last, some research on choking’ (Handley, 2013). His title encapsulates some of the frustration that has clung to choking first aid since its earliest rudimentary attempts were reported by Gross in the 1850s and following the promotion of Heimlich’s abdominal thrust in the 1970s. The root of the frustration for Handley and others concerned with choking death prevention lies in the absence of solid scientific evidence for the efficacy of these techniques (Handley, 2013; Hoffman, 1982; Montoya, 1986; Soroudi et al., 2007).

Despite wide public acceptance of first aid techniques for choking and their life saving properties, the efficacy of all of the techniques used since the

1980s have repeatedly been questioned by the medical fraternity and first aid organisations, with techniques frequently going in or out of favour (Bradley & Lerakis, 2015; Hoffman, 1982). Back blows, the Heimlich manoeuvre, lateral thrusts, chest thrusts and finger sweeps have all generated controversy. Heimlich, in promoting his manoeuvre, even characterised back blows (based on a misinterpretation of Gross's concerns about the technique) as being 'death blows' and claimed that their continued use was part of a political attempt to undermine his technique, in illustration of the politics of such first aid measures (Hoffman, 1982; Montoya, 1986).

At the foundation of the arguments for and against the various proffered individual techniques has been the underlying problem of identifying the mechanical forces required to dislodge an obstruction (such as airflow or chest pressure) and once decided, which technique best achieves it (Hoffman, 1982). Attempts to assess effectiveness through controlled studies are hampered by ethical considerations; Heimlich based the belief in his manoeuvre on the testing of four anaesthetised beagles (Montoya, 1986). Some studies have since been performed on anaesthetised humans (today not considered ethically appropriate) and corpses (Ruben & Macnaughton, 1978). Much of the human data available comes from anecdotal, non-medical sources with multiple inherent biases, which include only the reporting of positive outcomes and attributing success to one technique when multiple techniques have been applied (Handley, 2013; Hoffman, 1982). Additionally but also under-reported, all techniques have been associated with adverse effects (Montoya, 1986).

The effectiveness of the various techniques has been questioned, as has the effectiveness of associated training. A review of typical training programs suggested that participants in first aid training may not gain the necessary skills or be able to retain them despite expectations of achievement (Eisenburger & Safar, 1999). Comprehensive skills for managing a choking event may also not be taught in first aid courses if the amount of time available to teach other skills such as CPR is limited (Sayre, 2005).

An increasing number of psychological reasons are being proposed for why those placed to respond to a choking event may refuse to do training in the first place or why, if trained, fail to provide aid if a choking event occurs. These reasons include denial of a family member's potential risk, fear of failure, fear of legal prosecution if they act in error, fear of causing injury, and performance anxiety related to attempting a technique in front of others (Eisenburger & Safar, 1999; Pearn, 2000).

Choking first aid has saved lives but it has also failed to save lives. Lack of identification, size, degree, and site of obstruction, along with time to access advanced aid remain fundamental determiners of outcome (Montoya, 1986); determiners that have not fundamentally changed in 250 years.

Returning to the quote above:

A Foreign Body Airway Obstruction (FBAO) is a life-threatening emergency. Chest thrusts or back blows are effective for relieving FBAO in conscious adults and children (Carey, 2014, p. 5).

This emphatic statement by the Australian Resuscitation Council implies that if techniques are applied they will be successful. While confidence-building and motivational, the insertion of 'some' in their statement, thus: 'Chest thrusts or back blows are effective for relieving **some** FBAO in conscious adults and children' (Carey, 2014) would be a more accurate statement. Indeed, in 2015, the authors of the 'American Red Cross Scientific Review on Obstructed Airway-Adult' made two telling conclusions:

There are no studies that provide evidence that there is any technique for resolving airway obstruction that is clearly better than other techniques (Bradley & Lerakis, 2015, p. 7); and:

The evidence suggests that it is better to do something than nothing when faced with a person having a foreign body airway obstruction (Bradley & Lerakis, 2015, p. 9).

The importance of acknowledging such limitations in first aid is not to imply it should not be attempted, but rather to tease out a number of issues that may be noteworthy in the reality of choking, which have not been focused on in

historical studies driven by intervention or prevention concerns. In Gross's day the only individuals carrying societal expectations and responsibility for preventing death in the case of a FBO were physicians. Death was frequently the outcome, and no doubt a painful part of the physician's job. Public first aid education programs have shifted some of this social expectation and responsibility to lay people more broadly: "...the responsibility of all..." according to the US Surgeon General, John Pearn (Pearn, 2000).

Those most likely to witness and respond to a choking event in at-risk adults are those with a familial or carer relationship to the person. However, choking first aid techniques, even when performed by the most technically proficient, may not prevent harm or death because of the characteristics of the FBO and the limits of the techniques employed. Additionally, the teaching of these techniques may not be adequate (Sayre, 2005). Further, there is evidence that the special circumstances of some at-risk adults, such as severe physical disabilities, may make the application of first aid techniques extremely challenging (Guthrie & Roddam, 2011). Even those at-risk adults who have their obstruction removed and receive 'successful' CPR by bystanders or paramedics and make it to hospital may sustain significant brain damage and the consequences that that entails (Inamasu et al., 2010). What was an instant death in the 1700s may now be a drawn out process in an intensive care unit for days weeks or months. In the 21st century, preventing harm and trying to preserve life if a choking event occurs may be simple if the FBO is in the right place, is of the right degree and size to be easily removed, and if people are present and able to appropriately intervene, or the choking reality may be extremely complex.

Knowing who might be more likely to fatally choke rightly raises questions of how can we preserve life, but equally, having failed to 'cure' choking after 250 years, it also raises questions about could we be managing choking-related death better or differently? In contemplating the 'facts' surrounding choking many questions arise, including whether choking should be discussed as a part of advance care planning (Wagemans et al., 2017) for at-risk adults, should choking be acknowledged as not always preventable/

remediable, and do we (and if so how do we) need to support those who at various levels become involved in choking events. If embarking on a third 'truth seeking' mission prompted by questions such as these, then there are other issues that might need to be faced. Such issues are likely to include a need to balance risk, prevention and quality of life considerations. The second 'hot spot' in contemporary discourse around preventing choking risk and fatality is texture modified food.

Navigating the anomalies: Choking and texture modified food

Texture modified food and fluid (TMF) is a dominant strategy used by speech pathologists to compensate for dysphagia and manage its risks of aspiration, malnutrition, dehydration and choking (Cichero et al., 2013; Steele et al., 2015). It is however a strategy that is not without problems both physiological and social; particularly in the area of choking. The following is an overview of some of the tensions identified in this area that have relevance to choking in the contemporary space.

Food and choking

The connection between food, choking and death is an unavoidable one. An autopsy makes it possible to point to an obstruction and identify unequivocally that it is food and generally of what kind and amount (Blaas, Manhart, Port, Keil, & Buttner, 2016). However, the relationship between food and choking is complex; creating ambiguity and at times controversy as to its exact causal link given the multi-factorial nature of choking and how it should or could be managed (Appelbaum et al., 1992; Ekberg & Feinberg, 1992; Sharp & Bryant, 2003). In order to understand its significance to both the social context of choking and choking prevention, a brief consideration of its relationship to a broader contemporary 'hot spot', that being food and its medicalisation, seems pertinent (Hughes & Neal, 2000; Hung & Chaudhury, 2011). This area is highly complex in its own right and therefore the following will briefly touch on key points that underpin some of the current prevention and social issues as they relate to choking.

The importance of food

McHorney et al. (2000, p.115) observe that “dysphagia affects the most cardinal of human functions, the ability to eat and drink”. There has been much written on the importance of food and drink beyond their physiological function of maintaining the body. Food and drink have been symbolically linked to the social, cultural, spiritual and emotional wellbeing of individuals, their immediate carers and the larger community (Crogan, Evans, Severtsen, & Shultz, 2004; Hughes & Neal, 2000; McClement, Degner, & Harlos, 2003; McInerney, 1992). The intimate relationship of food and drink with many of the elements that make up the perception of quality of life, including ‘simple’ pleasure, can make it a highly charged issue when changes are proposed in response to dysphagia (Colodny, 2005; Kaizer et al., 2012; Kenny, 2015; Sharp, 2006). Texture modified food has been identified as negatively impacting on quality of life (Keller et al., 2012; Kenny, 2015; Vogel et al., 2014). An individual may not realise that certain foods or drinks are a part of their experience of life quality until such foods or drinks are changed or are not available to them (Sharp, 2006). Essentially food – physiologically, socially, emotionally, and spiritually – matters to people.

Biologically, food and drink is essential to the maintenance and survival of the body (Hughes & Neal, 2000). From a mechanistic perspective, the human machine needs “fuel” (Hughes & Neal, 2000, p. 1103). When medical conditions or illness disrupt the ability to ingest the necessary variety and amount of food and fluid required for health or indeed life, medical intervention becomes focused on correcting or overcoming the problem, either by changing the form of food, its delivery mechanism, or both. Under these circumstances, the delivery of the necessary nutrients and fluid required by the body becomes medicalised (Lipman, 2003). Food and drink – conceptually, practically, and symbolically – transforms to a therapy or intervention. This change is not just one of form but comes with the gravitas of a required ‘treatment’ necessary to preserve life; a prescription that comes with an implied expectation of adherence. Timothy Lipman (2003) artfully challenges this expectation and explores, specifically in regard to tube

feeding, how this change from food as we know it – with all its emotional and social connotations – to a medical treatment may be perceived. He comments that artificial nutrition and its realities (constructed clinically as a positive treatment option with obvious benefits), far from being inscribed with the nurturing and healing symbolism of chicken soup, is instead:

...non-volitional, forced, invasive delivery of artificial, limited, and fixed substrates associated with finite morbidity and mortality (Lipman, 2003, p. 94).

Trying to reconcile the social importance of food and all it might represent to an individual with its alteration into a treatment regimen prescribed by a health professional, can create major conceptual conflict as social and medical constructs clash (Furst, Connors, Bisogni, Sobal, & Falk, 1996; Sharp & Bryant, 2003). This conceptual conflict, though marked, may not impact on the aim of risk prevention and preservation of life if both parties are equally invested in these goals, and more traditional social constructs around food and drink can be abandoned or refashioned. If the person finds this abandonment or refashioning overwhelming however, then the desire to maintain some or all of the food-related connections with belief, pleasure and even perception of what makes their life worth living, will potentially bring them into conflict with those who have different views and beliefs and who often, with the best of intentions, want to change what and how they eat (Colodny, 2005; Kaizer et al., 2012).

Tube feeding, as a medical intervention designed to provide adequate nutrition in a variety of scenarios including severe dysphagia, has when challenged led to diverse debates, including whether food – whatever its form – is basic care, how quality of life is judged, and the limits to autonomy, decisional capacity, and substituted decision making (Sharp, 2006; Sharp & Bryant, 2003). Such debates have engaged the areas of law, ethics, religion and more (Casarett, Kapo, & Caplan 2005; Clarke, Harrison, Holland, Kuhn, & Barclay, 2013). Food matters; changing food matters; caring for and protecting people matters. These concerns matter; their role in dysphagia and choking care however is not without controversy.

Entering the texture modified food space

Long before tube feeding is considered necessary (if ever) or when tube feeding is not considered an option due to inefficacy, as in dementia care (Finucane, Christmas, & Travis, 1999), the texture modification of food and drink may be considered as a compensatory treatment for dysphagia in order to alleviate its associated risks (Cichero et al., 2013). Seemingly not as dramatic or invasive an intervention as tube feeding, texture modification will nevertheless be dogged by similar issues, connected to both the way it is perceived and the desire by some to refuse it (Appelbaum et al., 1992; Kaizer et al., 2012; Kenny, 2015), and will bring additional issues, particularly in regard to choking (Berzlanovich et al., 2005).

The normality of modifying food

In reviewing what is happening in the contemporary space of texture modified food, it is important to note that humans naturally modify the consistency of food and drink on a daily basis for a range of biological, pleasure and other, more or less innocuous reasons. A sheaf of wheat has sound nutritional value but it is difficult to eat unprocessed and carry under your arm throughout the day. Ground down, its natural texture fundamentally changed, it can be manipulated and combined to create a range of pleasurable additional texture consistencies: crusty bread, moist cake, and if processed into a cereal such as Weet-bix it can be then soaked in milk and mashed into a consistency easy to orally process after a trip to the dentist, or more comfortably swallowed in the presence of a sore throat. Different consistency foods, in a progression from minimal texture (pureed food) to the full range of textures (such as unmodified fruit, vegetables, bread, meat) are used in a graded process to safely move babies from ingesting milk to solids (Cichero et al., 2013).

Modified food as a compensatory treatment?

The normality of changing food consistency to enhance ingestion makes pinpointing the moment texture modified food moves from an informal adaption, to ease swallowing difficulties, to a formal compensatory treatment for

dysphagia, difficult. Both those with swallowing problems and those who provide care for them have probably been informally modifying food consistency or avoiding different consistencies to make swallowing easier (Chen et al., 2009; Watt & Whyte, 2003) throughout history. As such, the texture modification of food may be perceived as logical, caring and innocuous by many. Based on ‘common sense practice’, many an institutionalised person with swallowing difficulties has likely been ‘placed’ on a pureed diet; the value of such practice probably based on the logic of reversing a child’s natural food progression (Cichero et al., 2013) for safety.

However, according to Swan and colleagues (Swan, Speyer, Heijnen, Wagg, & Cordier, 2015), in recognition of the potentially negative quality of life implications of pureed food, it should be considered the option of last resort and following careful assessment. In this conceptual space what is of particular note is that, if the texture modification of food is considered benign, perceived to reduce choking, and linked to normal behaviour and practice, then the belief may exist that people are unlikely to refuse it. From this logic its instigation should not require consent as it is not a treatment per se, but merely a sensible adaption (Sharp & Bryant, 2003). The medicalisation of texture modified food therefore may come with pragmatic advantages; if its use is based on a formal assessment and consent, this may prevent people being placed on a restrictive treatment regimen without due consideration (Keller et al., 2012).

Medicalising texture modified food

Texture modified food is frequently used by speech pathologists in a clinical setting to manage dysphagia (Steele et al., 2015). It likely owes much of its ‘treatment status’ as a compensatory technique for dysphagia to the work undertaken by Jeri Logemann outlined in the previous section (Miller & Groher, 1993). Logemann’s development of the barium swallow technique permitted not only an internal observation of the phases of swallowing – an opportunity to see ‘what was happening’ – but also an opportunity in the case of swallowing disorder to see if different drink or food consistencies helped or

hindered swallowing efficiency and safety (Miller & Groher, 1993). This ability to internally study the swallow and potentially its relationship to different food and fluid consistencies is likely a key moment when conceptually the informal, at times ad hoc, use of texture modified food (Keller et al., 2012) shifted from ‘common sense practice’ and potentially initiated by anyone, to a formal compensatory treatment (with strict texture parameters) prescribed by a health professional based on physiological assessment and diagnosis.

That said, despite advances in the understanding of the biomechanics of dysphagia (McHorney et al., 2000), the relationship of food consistency to physiological processes is not well understood; the study of both areas is still considered to be in its infancy, with more empirical knowledge needed (McHorney et al., 2000; Raut, McKee, & Johnston, 2001; Steele et al., 2015). With regard to choking, due to the ethical problems of studying choking physiology directly (Hunsaker & Hunsaker, 2002; Japanese Food Safety Commission, 2010), the connection between food consistency and ‘catastrophic aspiration causing asphyxia’ has to be extrapolated from effects seen in disordered swallowing videofluoroscopy studies such as the retaining of residue²⁸ in the oro-pharynx after swallowing, and the biomechanical observations of aspiration episodes that may have relevance to choking (Japanese Food Safety Commission, 2010; Paintal & Kuschner, 2007; Steele et al., 2015). Observation and self-reporting is an added diagnostic tool used to assist the understanding of the food-choking relationship, and given the multi-factorial nature of choking has to include a consideration of other factors such as gorging, speaking when eating, and/or poorly skilled feeders (Ekberg & Feinberg, 1992; Hadjikoutis et al., 2000). A further main source of information about dysphagia biomechanics is forensic reporting on the size and composition of the substances – food or otherwise – that people have fatally choked on (Berzlanovich et al., 1999; Dolkas et al., 2007; Hashmi et al., 2004; Leadbeatter, 1989).

²⁸ The strength and efficiency of a normal swallow is unlikely to leave food residue coating the oro-pharynx. Such residue could potentially dislodge after a swallow is complete, and uncontrolled fall into the airway which it might block.

Despite multiple gaps in knowledge, texture-modified food or specific consistency diets are recommended throughout the world by appropriately skilled health professionals (in Australia, a speech pathologist²⁹) (Balandin et al., 2009; Cichero et al., 2013) as a therapeutic intervention to promote easier and safer swallowing based on the diagnosis and assessment of dysphagia (Keller et al., 2012). The use of texture modified diets as a clinical intervention to assist with dysphagia management however is not without its problems, based on such issues as their definition, standardisation, acceptability and efficacy; issues which currently occupy the contemporary landscape in this area (Keller et al., 2012).

Teasing this out a little further, in order to link the appropriate texture to the particular swallowing problem, an assessment of the person's swallowing needs to be performed, so that the texture has a meaningful and positive impact (Cichero et al., 2013). To promote this aim a range of possible texture options (diets) need to be defined, once defined standardised, and then uniformly prepared and provided across all the possible contexts a person with dysphagia may inhabit, so that everything they eat is appropriate to their level of swallowing function and its enhancement (Cichero et al., 2013; Steele et al., 2015).

Currently, while texture modified diets are used internationally in dysphagia management, multiple terms are used to describe these different diets, making it difficult to compare and study them to gather the necessary evidence for their use and effectiveness (Steele et al., 2015). Considerable research has been done to address problems with standardisation. As noted in Chapter 1, countries like Australia have established their own standards (Dietitians Association of Australia & The Speech Pathology Association of Australia, 2007), with an international initiative now driving global standardisation (IDDSI, 2016). In Australia there are national standards for food and drink texture modification to manage dysphagia and associated risks. There are three levels of texture modification for food and fluids. The

²⁹ In other countries other professionals such as occupational therapists may assess and manage dysphagia.

textures are defined and apply to all food and fluids, across all food groups and meals (Atherton, Bellis-Smith, Cichero, & Suter, 2007).

These diets require a systematic alteration of all food and drink, including eliminating certain textures and foods/drinks from the person's diet. They create restriction (Chadwick et al., 2006) and should only be applied due to clinical need (Keller et al., 2012). According to Keller however, evidence suggests that they may be applied with no formal assessment, and diets such as 'pureed' may be initiated to manage feeding issues and staff-related issues, not linked to an underlying physiological need (Keller et al., 2012).

The efficacy of texture modified diets

Little is known about texture modified diets and whether they achieve what they purport to (Keller et al., 2012). Due in part to the problems above it has been challenging to prove the efficacy of these diets in achieving compensation of swallowing function and reduction of risk. Systematic reviews performed to identify studies on these diets and their efficacy have shown limited quality studies in the area (Andersen, Beck, Kjaersgaard, Hansen, & Poulsen, 2013; Steele et al., 2015). Those studies considered to be of value have presented limited positive findings, with reviewers concluding that there is a lack of strong evidence that texture modified food³⁰ is effective in preventing or reducing the impact of dysphagia (Andersen et al., 2013; Steele et al., 2015). An association between texture modified food and under-nutrition has been indicated (Keller et al., 2012) and their negative effect on quality of life has been noted earlier (Keller et al., 2012; Kenny, 2015; Vogel et al., 2014).

TMDs remain widely used however to mitigate the risk of choking (Cichero et al., 2013), based on the prevailing presumption that the compensatory effects of such a diet on dysphagia would automatically reduce the risk of choking. Steele et al.'s (2015) work indicates that the efficacy of TMDs in regard to dysphagia is not conclusive and when it is successful depends on

³⁰ The findings are more favourable for TM drinks reducing aspiration.

individualised careful assessment of the at-risk adult. Such a conclusion would also seem appropriate to apply in regard to choking.

While some foods have been singled out as of particular risk in regard to choking (Dietitians Association of Australia & The Speech Pathology Association of Australia, 2007; Japanese Food Safety Commission, 2010; Wick et al., 2005), forensic studies show people can choke on any type and consistency of food. While there may be particular foods that either reduce or increase choking in specific at-risk adults, the range of food people can choke on suggests there is no universally safe texture that can automatically be applied to avoid risk. Even when assessing an at-risk adult individually, the exact nature of the link between swallowing physiology, particular food consistencies and choking is based on supposition rather than empirical evidence, though such evidence is being sought (Raut et al., 2001).

The lack of evidence of the effectiveness of such diets is sobering given how much confidence is invested in their use. A possibly inflated belief in their value becomes a particular tension when at-risk adults wish to refuse them.

Ethical considerations and texture modified food

“Patients choosing not to comply with prescriptions for modified boluses is anecdotally a common issue, with many expressing a strong dislike of the altered textures” (Swan et al., 2015, p. 2448). Texture modified diets feature as one of the elements of dysphagia that reportedly impacts on the quality of life of those with dysphagia (Keller et al., 2012; Kenny, 2015; Vogel et al., 2014). Therefore in the context of the many losses associated with dysphagia and the conditions that often underlie them (Kaizer et al., 2012), at-risk adults or their substitute decision makers may choose to refuse outright the recommendation of a TMD or the degree of texture modification suggested, because of its negative impact on their life (Keller et al., 2012; Kenny, 2015).

The rejection of this one strategy that so many are confident will provide safety brings ethical considerations and commentaries into the texture modified food space (Kenny, 2015). As a medicalised treatment strategy, its

recommendation and refusal initiates a ripple effect of concern in regard to such considerations as compliance, autonomy and its associated informed consent/refusal, duty of care and liability, values in regard to the sanctity of life, and issues of conscience (Kaizer et al., 2012; Kenny, 2015). Such issues echo the debates around tube feeding, again highlighting the ‘treatment’ nature of TMF (Lipman, 2004; Sharp, 2006; Sharp & Bryant, 2003).

Ethical commentaries in the TMF area refer to both the challenge of ensuring in the context of refusal that at-risk adults or their decision makers have been fully informed, and the implications of refusal for those providing care to vulnerable adults (Chadwick et al., 2006; Kenny, 2015). Two elements around food and risk are particularly pertinent to carers in this conceptual space. The medical conditions underlying choking risk may mean an at-risk adult cannot prepare and access their own food, therefore others become involved in food provision. If the at-risk adult will not eat TMF for whatever reason, then others may have to prepare and provide food for a vulnerable adult which they have been told is unsafe (Kaizer et al., 2012). More intimately, if the at-risk adult cannot feed themselves then carers, who may or may not agree with their refusal choice, may be expected to place ‘unsafe’ food in the person’s mouth, manage a choking event if it occurs, and be involved with a subsequent death and all its immediate and long term consequences (Kaizer et al., 2012). According to Hughes and Neal: “The giving of food also has a social imperative, food becoming symbolic of the relationship between giver and receiver. The giving of food is an act of nurturing and community” (Hughes & Neal, 2000, p. 1103). The receiving of unwanted food or the giving of food considered to compromise safety both carry the potential to seriously undermine the relationship between giver and receiver.

Risks – physical, psychological and social – associated with TMD refusal therefore exist for both the at-risk adult and those who may be required to care for them. Despite evidence that other factors such as fast feeding rates (Berzlanovich et al., 2005), poor positioning, not providing prompts, poor spoon feeding techniques, and lack of supervision may be implicated in poor

safety around ingestion (Chadwick et al., 2006), the confidence in the safety-promoting effects of TMF may make even speech pathologists reluctant to continue to provide care if such prescriptions are refused.

Attempts to tease out the above issues and provide ethical guidance and frameworks are appearing in the contemporary literature (Kaizer et al., 2012; Kenny, 2015). However in order to tackle these issues there needs to be further clarity regarding some of the more confronting aspects about choking and its management.

Choking and tensions between texture modified diets and first aid

TMF as a management strategy in dysphagia care is an area that remains under construction; it is an area of knowledge in flux. However concerns about choking are a major reason for TMF prescription (Keller et al., 2012). Adding to the evolving thought around choking and its management is the – albeit currently sparse – literature that links choking with the two ‘hot spots’ being discussed. This literature, based on both non-fatal and fatal choking events –perhaps counter-intuitively – proposes that semi-solid diets should not be recommended as they themselves have been shown to increase the risk of choking and fatality (Berzlanovich et al., 2005; Ekberg & Feinberg, 1992; Kennedy, Ibrahim, Bugeja, & Ranson, 2014; Mittleman & Wetli, 1982). This recommendation directly challenges the long-held general and clinical belief that such a food consistency would be protective. There are two parts to the assertion that semi-solid diets should not be used; they increase risk and they increase fatality.

The first part of the assertion is linked to the difficulty in managing the consistency of TMF physiologically (Ekberg & Feinberg, 1992) and the frequency with which it is forensically noted in autopsy studies. This appears to be not widely known or embraced given that these diets are still being recommended and used (Keller et al., 2012). However, references to the recommendation that semi-solid diets not be used are appearing increasingly in the literature (Steele et al., 2015), which may prompt more debate. Such debate may need to explore whether – given the multi-factorial nature of

choking and what is not yet known about the connection between swallowing physiology, food texture and choking – any dietary consistency can definitively be promoted or dismissed. Additionally, if semi-solid diets are more comfortable for some people to swallow and/or address other risk factors such as poor food intake, then further resolutions between balancing competing risks and quality of life considerations may need to be addressed.

The second part of the assertion, that is not to recommend semi-solid food for reasons of safety if a choking event occurs, is linked to the difficulty using current first aid techniques in removing such a food consistency from the airway. Given the limitations of first aid previously discussed, this finding may be less likely to be debated (Berzlanovich et al., 2005; Mittleman & Wetli, 1982; Wick et al., 2005) and indeed may be the key feature of the lack of safety of these diets. Of particular consideration in light of this counter to texture modification is the perhaps inappropriate importance it is given by others and the conflict created when people wish to refuse it. Swan and colleagues (2015, p. 2454), in discussing the negative effects of TMD on QoL, pose: “Is there a time when the disadvantages [of TMF] will outweigh the benefits?” The contemporary space of choking suggests that this time may be here, and not for QoL reasons alone.

The purpose of drawing together some of the key elements surrounding choking in the contemporary space is to illuminate both its complexity and attendant tensions, which will provide background to the study data. Food is important to most people, not only for the pleasure it gives in the moment and its life-sustaining function, but also for its symbolic relationship to many of the things people value in life. Fear is a common reaction to the risk and manifestation of choking, contributing to stress for both at-risk adults and their informal and formal carers. Fear may make people want to reduce risk, but quality of life considerations may make for decisions which, while not negating a desire for risk reduction may trump it, as people try to maintain or promote their quality of life. The texture modification of food to assist with ingestion is normal and natural and informally is used by at-risk adults and others to aid swallowing. The greater the texture modification the greater the

potential impact on quality of life. The placing of someone on such a diet without proper assessment and for reasons other than the persons benefit is inappropriate.

The medicalisation of food as manifested in TMDs has advantages and disadvantages and can raise significant ethical dilemmas around its use and acceptance. Attempts to promote and establish the advantages of TMF in a medicalised form through the development of standards and consistency are still under construction. The efficacy of texture modified food, while commonly used clinically to address the risks of dysphagia and reduce choking, is not widely understood or proven. There is evidence that some levels of texture modification used therapeutically may itself increase the risk of choking and fatality. If choking events cannot be prevented for whatever reason, choking first aid due to its limitations (including but not limited to its relationship to TMF), may not be able to prevent death. The contemporary space on choking, far from being one of confidence and surety built on 250 years of truth seeking is still in flux; the ability to prevent and intervene effectively is under challenge, not just because of its limitations, but also related to the enduring narrowness of perception in addressing the complexity of choking.

Concluding remarks

This literature review presents a historical view of the theory of prevention that currently dominates how choking is viewed and managed. It identifies that social phenomena surrounding choking, when acknowledged, are largely conceptualised through the lens of prevention and intervention; a construction that judges social phenomena based on whether or not they function as a risk factor in the clinical context. A brief overview of contemporary issues challenges whether maintaining a prevention-and-intervention focus, embedded in a mechanistic view of choking, is both sufficient to meet the needs of at-risk adults and carers and sustainable as a sole approach to care in the area, given the multiple other issues that emerge there.

This study aims to add to what is known about choking by exploring its social context via a consideration of forensic data (specifically coronial reports linked to choking fatalities), and by doing so identify what may be important for care based on a perspective beyond the lenses of physiology and prevention. It will explore the social context of choking through the stories – as represented in coronial reports – of at-risk adults and their carers who experienced living with choking risk and choking fatality. To this end this study uses classic grounded theory methodology – which will be described in the next chapter – to illuminate the social context of choking and investigate the possibility of a new theory that may meaningfully expand thinking on the topic and how care might be enhanced.

CHAPTER 3: METHODOLOGY

INTRODUCTION

In the early 1960s Dr Roger Haugen, whom we met in Chapter 2, was conducting autopsies and removing un-masticated food from the airways of those who had died. In so doing he outlined his now classic description of the physical manifestation of choking; a description that with his expressive use of language, spoke of ‘fashionable restaurants’ and ‘poor table manners’, and hinted at but did not explore social forces that might contribute to choking (Haugen, 1963; Sayre, 2005). Also temporally connected, another 1960s event proved significant to this study as two social scientists, Barney Glaser and Anselm Strauss, were formulating a research methodology that would ultimately clarify my research journey and potentially contribute to how choking and its management might be perceived in the 21st century (Glaser & Strauss, 1967).

In the mid-1960s, Glaser and Strauss were studying the dying experiences of those in hospital (Glaser & Strauss, 1966). They described their study thus: “In general, our project was focused on what kinds of thing happen around patients as they lie dying in American hospitals” (Glaser & Strauss, 1966, p. 8). The project presented in this manuscript is ‘in general focused on what kinds of thing happen around at-risk adults as they live and die with choking risk’.

SECTION 1: GROUNDED THEORY

Goal of grounded theory and rationale

As Glaser and Strauss worked on their project and confronted the challenges it presented, a new methodology for research began to coalesce, which they named Grounded Theory (GT). On completing their original study *Awareness of Dying* (1966), they went on to publish *The Discovery of Grounded Theory*

(1967). The goal of grounded theory methodology was to generate theory from social research data, rather than use data to test existing or partially formed theories, which was the predominant approach of social research at the time (Glaser & Strauss, 1967).

Since 1967, various versions of grounded theory have appeared, championed individually by Strauss and new authors such as Charmaz (Charmaz, 2006; Evans, 2013; Strauss & Corbin, 1998); each new version according to Kenny and Fourie (2015) largely reflecting differences in the position of literature, philosophical roots, and coding procedures (Glaser & Strauss, 1967; Kenny & Fourie, 2015). Glaser has continued to champion 'classic' GT (based on the original text written with his colleague Strauss), summarising it as:

...simply a set of integrated conceptual hypotheses systematically generated to produce an inductive theory about a substantive area. Classic GT is a highly structured but eminently flexible methodology. Its data collection and analysis procedures are explicit and the pacing of these procedures is, at once, simultaneous, sequential, subsequent, scheduled and serendipitous, forming an integrated methodological "whole" that enables the emergence of conceptual theory...

(Glaser & Holton, 2004, p. 3).

With some modification, particularly with respect to the collection of data, it is principally on the original conceptualisation and suggested method of GT that this current study is based.

GT as methodology and method: Principal tenets and actions

GT and being open

Grounded theory as a methodology has a number of tenets which conceptually underpin and drive it. These tenets find expression in the method; the techniques or procedures used to inductively derive theory from data. Glaser and Strauss wanted researchers to approach data from as open

a position as possible, unbound by previous conceptions of the data and what it would offer (Glaser & Strauss, 1967). To this end, a major principle was for the researcher to be 'literature naïve'; to avoid engagement with previous research on the specific topic being studied, and thus allow the data to teach the researcher what it had to offer rather than the researcher attempting (consciously or unconsciously) to try and fit the data into a preconceived model or previously proposed theory (Glaser, 1978, p. 31).

As part of the method of classic GT therefore, the literature pertaining to the topic is read near the end of analysis after the key categories and theory have begun to emerge (Glaser & Strauss, 1967, p. 37). This leaves the research unrestrained as much as possible by previous knowledge or edicts on the topic. The literature is then used to further refine the theory that has emerged by comparing and contrasting it with previous theories presented on the topic. The research studies that lend themselves to grounded theory methodology are those therefore that are not trying to prove or disprove something or verify theories that already exist but rather to explore, discover and understand, thereby making the suspension of previous theories and viewpoints desirable (Glaser & Strauss, 1967).

Classic GT has been criticised for its requirement of literature naivety, largely based on arguments around its purported impracticality. Glaser and Strauss were mindful of this:

Of course, the researcher does not approach reality as a tabula rasa. He [sic] must have a perspective that will help him [sic] see relevant data and abstract significant categories from his [sic] scrutiny of the data.

(Glaser & Strauss, 1967, p. 3).

The intention of GT in its original form was realistically not premised on a need for total naivety but for maximising openness to the data and what it could offer. Literature was not abandoned, but strategically placed in the process to maximise theory generation. Theory would emerge from confidence in the methodology and the systematic application of its

procedures, not based on previous thought on the topic or how the world was constructed (Glaser & Strauss, 1967).

GT and philosophical alignment

In *Discovering Grounded Theory*, Glaser and Strauss promoted GT as being able to be used with any kind of data; qualitative, quantitative or both. They shied away from stating any ontological or epistemological position; seeing GT as a general research methodology that could be used regardless of the philosophical position of the researcher (Glaser & Strauss, 1967).

GT's frequent use with qualitative data however has aligned it in the thoughts of many of its reviewers with qualitative research design with its inherent challenges, particularly those of accuracy and subjectivity (Glaser & Holton, 2004). These challenges are at least partially addressed by the imperative in qualitative research to declare a philosophical stance for the purpose of transparency and to identify influences potentially affecting accuracy of description (Glaser & Holton, 2004). Glaser refutes the need for this in classic GT:

Grounded theory is not about the accuracy of descriptive units. It transcends descriptive methods and their associated problems of accuracy, interpretation, and constructionism. In so doing grounded theory offers qualitative researchers a systematic and rigorous method for developing theory but it requires that they transcend the canons of the qualitative paradigm if they are to assess its power about social processes.

(Glaser, 2003 in Holton, 2008, p. 5).

Glaser has stated his belief that (classic) GT "...stands alone as a conceptual theory generating methodology" (Glaser & Holton, 2004, p. 9) and is therefore philosophically neutral (Holton, 2008). Multiple arguments however, have been mounted in regard to this supposed philosophical neutrality, with a number of different philosophical underpinnings suggested (Birks & Mills, 2015; Breckenridge, Jones, Elliott, & Nicol, 2012; Charmaz, 2006; Kenny & Fourie, 2015; Urquhart, 2002). Positivism (whereby reality is understood

through observation and scientific method) has been frequently suggested as the influence behind classic GT, partially based on Glaser's earlier career influences and the use of some terms in *Discovering Grounded Theory* which were associated with positivistic leanings (Charmaz, 2006, pp. 6-9; Kenny & Fourie, 2015). Stern however proposes the idea that Glaser and Strauss originally used positivistic language in an attempt to help their audience (positivist sociologists) understand GT (Stern in Morse et al., 2009, p. 59).

Throughout the methodological debates, Glaser has remained steadfast in viewing classic GT as separate from both traditional qualitative research design and the need for a philosophical position (Glaser & Holton, 2004). GT as a methodology may not *need* a philosophical position to achieve its goal given that it is not focused on descriptive accuracy and "can adopt any epistemological perspective appropriate to the data and the ontological stance of the researcher", but the researcher using GT will come with a world view (Holton, 2009, p. 38).

What GT as methodology and method tries to achieve is for the researcher to enter the field and explore the data and emerging theoretical concepts with as much openness and through as many different perspectives as possible (Holton, 2009):

GT's paradigm is to trust to emergence and by constant comparison, conceptualize the latent patterns. The social organization of life goes on and on. The GT goal is to discover it conceptually not describe it...The worldview of GT is to allow the researcher the freedom to discover and generate conceptual theory about 'whatever' and not preconceive its nature. Its limits are the researcher's self and resources.

(Glaser, 2003 in Holton, 2008, p. 6).

With respect to the above debate, as an individual researcher I feel ambivalent about my ontological and epistemological position; my stance on the nature of being and how we gain knowledge and differentiate truth and falsehood and perceive reality is somewhat different in my personal life from how I view, experience, and promote it in my professional life. One of the

reasons classic GT resonates for me is Glaser's contention that it functions separately from a philosophical position. This to me means I am not forced to claim an alignment with a philosophy that does not sit comfortably with me as a whole person, and indeed fluctuates. That said, I acknowledge the arguments and agree that it is important to be aware of one's background influences, as such knowledge is a step in being open to other philosophies and ways of perceiving data.

To this end, I am aware in my work life that my professional training as a speech pathologist and how I function in that 'reality' is heavily influenced by positivism. This study is linked to my work life and therefore I believe is likely to have positivism as at least a partial underlying philosophical influence. My affinity with classic GT in regard to philosophical stance is perhaps summed up by author and qualitative researcher Suddaby, who asserts that GT was:

...founded as a practical approach to help researchers understand complex social processes. It was also designed as a method that might occupy a pragmatic middle ground between some slippery epistemological boundaries.

(Suddaby, 2006, p. 638).

As I personally slip between epistemological boundaries but seek permission to move beyond positivism in researching this topic, classic GT seemed an appropriate choice for both my data and me as a researcher.

GT and theoretical sampling and saturation

A fundamental feature of GT is that data collection and core elements of analysis (coding, constant comparison, and memo writing) are not set out as linear steps but all can and do happen simultaneously, each informing the other, and allowing for the flexibility to seek more data based on analysis (Glaser & Holton, 2004).

Theoretical sampling

Theoretical sampling is a key element of GT and is directed at supporting and advancing theory development. Conceptually it aims to do this by encouraging sampling to be flexible, sensitive and responsive to the data and what is emerging conceptually from it (Glaser & Strauss, 1967). Sampling remains open so that additional data can be collected or new data sources identified and included until the researcher believes they have reached saturation of categories.

Saturation

Theoretically, data collection ceases when theoretical saturation is reached. Kathy Charmaz suggests that saturation is reached "...when gathering fresh data no longer sparks new theoretical insights, nor reveals new properties of your core theoretical categories" (Charmaz, 2006, p. 113). Suddaby views saturation as a particular challenge in GT: "Because grounded theory research uses iteration and sets no discrete boundary between data collection and analysis, saturation is not always obvious, even to experienced researchers" (Suddaby, 2006, p. 639).

Saturation is both a data and analysis issue and a pragmatic one according to Glaser and Strauss: "The criteria for determining saturation...are a combination of the empirical limits of the data, the integration and density of the theory, and the analyst's theoretical sensitivity" (Glaser & Strauss, 1967, p. 62). Saturation is therefore more of a process aim to strive for rather than a definitive endpoint required before a theory can be claimed. Some authors prefer Ian Dey's (Dey, 1999, p. 117) term 'theoretical sufficiency', referring to sufficient data to form a theory over 'theoretical saturation', as a better way of expressing how researchers manage grounded theory practically while still properly analysing the data (Andrade, 2009; Charmaz, 2006). Theoretical sufficiency seems a more workable concept, as when working with highly complex and/or voluminous data, a desire or 'obsession' for saturation may be never ending, as captured in this statement by Glaser and Strauss:

When generation of theory is the aim, however, one is constantly alert to emergent perspectives that will change and help develop his [sic] theory. These perspectives can easily occur even on the final day of study or when the manuscript is reviewed in page proof: so the published word is not the final one, but only a pause in the never-ending process of generating theory.

(Glaser & Strauss, 1967, p. 40).

New concepts or properties may thus continue to arise, but at some point the researcher must make the decision as to whether a theory has emerged with sufficient substance to be of value.

GT and coding, constant comparative analysis and memoing

Coding, constant comparative analysis and memoing are all principal components of GT. "The conceptualisation of data through coding is the foundation of GT development" (Glaser & Holton, 2004, p. 12). Coding encourages the researcher to engage in-depth with the data by fracturing it into fragments, and coding (labelling) these fragments conceptually. As data is collected and coded these fragments are constantly compared with each other and start to group together to form categories. Initially these categories may be substantive, but as categories are compared the relationships between them and the questions stimulated by them begin to illuminate higher levels, and broader, more encompassing, conceptually abstract categories. During this process new categories emerge and initial categories collapse into others (Glaser & Strauss, 1967).

Constant comparative analysis is key to GT; as with coding and memoing its purpose is to move analysis forward and provide the opportunity for theory to emerge. The constant comparative analysis of data fragments and data categories (substantial and theoretical) illuminates the building blocks that link the ground (data) with the theory (emergence of a core category that both encompasses and explicates the building blocks). Inherent in this analysis is an openness to all incidents, "...similar or different, positive or negative..." (Glaser & Holton, 2004, p. 8), which have to be included in the emerging conceptual categories. This both challenges the researcher to push

beyond what might be expected to acknowledge all the data, and facilitates the emergence of theory that will have explanatory power for all the social phenomena being explored (Glaser & Strauss, 1967). Integral to coding and constant comparative analysis is memoing.

Memoing is another principal element of GT. “If the analyst skips this stage by going directly to sorting or writing up, after coding, he/she is not doing GT” (Glaser & Holton, 2004, p. 17). Memoing parallels coding and constant comparative analysis. Memoing in classic GT involves recording theoretical notes which explicate: the connections between categories; the hypotheses formed; conceptual impressions, ideas and insights; and decisions made. Memos are: “...continually capturing the...frontier of the analyst’s thinking...” (Glaser & Holton, 2004, p. 17). As a process, memoing occurs throughout analysis. As a part of the final elucidation of theory, these memos are sorted and used both to integrate and guide the writing up of the theory (Glaser & Holton, 2004).

GT and this study

Background

My journey as a researcher began in 2008. Up until that point I was (and remain) a speech pathologist working in a community-based training position, providing education to the informal and formal carers of adults with swallowing and communication difficulties. As part of my role I work closely with staff across different organisational settings such as aged care facilities (ACF), district hospitals, and group homes. I train and consult with staff from multiple health contexts and therefore am privileged in being exposed to the challenges faced by catering staff, personal care assistants, nurses, allied health professionals, service coordinators, and managers in providing dysphagia management. My opinion at that time was that both staff and organisations were struggling with managing dysphagia and choking risk, an opinion that seemed reflected in a number of contemporary coronial reports I was privy to as part of my professional role.

In 2008 a number of choking deaths occurred in close succession in public and private care institutions in my state of residence. This cluster of deaths, occurring in different types of health care contexts, appeared to be linked to the presence of dysphagia in all those who had choked and died. This link further suggested the possibility that there was an underlying problem with dysphagia management in these facilities. These fatalities increased awareness and concern about choking in at-risk adults in the primary health care division in which I worked. As a consequence of these deaths and my role, I proposed and was given the opportunity and encouragement to do an in-house research project exploring this issue, albeit 'off the side of my desk'. My exposure to a number of public coroners' reports lead me to believe that they were a rich source of data on both physical and environmental factors for choking. Coroners' reports had been used previously by medical and forensic researchers to identify risk factors for choking (Berzlanovich et al., 1999; Dolkas et al., 2007; Wick et al., 2005), but I believed there was value in exploring the data source from a speech pathology perspective.

This initial study was therefore clinically focused, with the goal being: *Prevention and management of choking in adults with identified or suspected dysphagia*, using coroners' reports as the data source. I had minimal research experience, having only previously undertaken a small research study as an undergraduate in the 1980s; however I had been a member of my state's social science ethics committee for a number of years after completing a Masters of Bioethics³¹ in 2007 so I was at least familiar with some of the major elements of research. This preliminary venture into research was qualitative, utilising content analysis as the method. It was descriptive in nature and did not aspire to more than further clarify risk factors already determined, identify new risk factors if present, and illuminate the environmental circumstances which might undermine the successful control of these factors. I was incredibly naïve and in hindsight can see I was one of those qualitative researchers who can quite rightly be challenged for not having a clear methodological approach (Suddaby, 2006).

³¹ The Masters of Bioethics was comprised of 3/4 course work and a theoretical dissertation

This original study had two impacts. The first was that the information identified was helpful clinically and provided many insights into what was required in training to manage dysphagia and choking risk. The second impact was that the data were so rich it illuminated the social phenomena that many at-risk adults and formal and informal carers in my clinical and teaching experience had alluded to in regard to choking risk and management. The social context of choking was far more complex than a focus on risk factors alone could elucidate.

My interest in the data, researcher naivety, and lack of research mentorship and control, in hindsight had in combination already led me to analyse the data far beyond description of events and the goal of that first study. In exploring the data I had begun, albeit at a rudimentary level, to use some of the tools associated with GT (though I did not know it at the time): labelling data fragments (coding); comparing and contrasting different phenomena (constant comparative analysis); and writing copious notes on what I was finding, what I thought it meant, and what I wanted to explore further (memoing). The complex nature of the social phenomena depicted in the coroners' documents and the overall compelling richness of the data had also already started to illuminate conceptual ideas embedded in the data. The data had me 'hooked', which eventually and via a circuitous route lead me to the School of Medicine with a desire to commence a PhD exploring the social context of choking and its implications for care, using the data from the original project.

Choosing Grounded Theory

In 2011 I began my PhD, armed with reams of paper filled with analysis and notes on over 200 coronial case transcripts³², and a desire to illuminate the social context of choking. I think both I and my initial supervision team thought that given how familiar I was with the data that this would be a quick dissertation! My early supervisors and I had a very rough start, which continued for a number of years. No one knew the data as well as I did and yet probably no one was less equipped to find a framework for it than me. I was sitting on a valuable mess that I had painstakingly initially analysed under the relatively loose title of 'content analysis', but without a defined methodological framework or clear direction.

As my research apprenticeship progressed however, circumstances intervened which lead to my gaining a new supervisor who enthusiastically dove into the mess with me. An interrogation of my analytic approach led her to speculate that I appeared to have been engaged in grounded theory methodology. When I read Glaser and Strauss's *Discovering Grounded Theory*, 256 at-risk adults who had died from choking and been subject to coronial investigation, their carers, and I myself had finally found our methodological home.

My study suited GT as it met the 3 indicators proposed for the methodology by Birks and Mills (2015): firstly, that *little was known* about the social context of choking and its implications for care; further, that *the generation of theory with explanatory power was a desired outcome for understanding the area* beyond a biomedical perspective; and finally, my first study had already shown that there was *an inherent process* (living with risk and death) *imbedded in the research situation that was likely to be explicated by grounded theory methods* (Birks & Mills, 2015, p. 17).

³² In the initial research project I did not have data from Western Australia (WA). To look at the social context of choking Australia-wide, WA data 2000-2010 was included in the PhD study giving a final study sample of 256.

Classic GT resonated with what I was trying to achieve, the analysis I had done and the analysis I still needed to do. Fortuitously I had not undertaken a literature search specifically relevant to the social context of choking or what theory drives choking management. My knowledge of the literature professionally and from the first study was based on the physiology of choking and the clinical assessment and management of choking risk. I was not approaching the topic as a 'tabula rasa' but nor was I wedded to the literature (Glaser & Strauss, 1967, p. 3). Rather, the literature I was familiar with gave me a contrasting perspective from which I could see relevant data and concepts that were more socially than clinically based, which proved advantageous. Additionally, my analytical approach to date had been sympathetic to GT and with additional knowledge of the methodology and method I could further apply its tenets and procedures.

The only real stumbling block to using classic GT relatively late in my research journey was my not having used theoretical sampling (a fundamental tenet of GT). Coming late to GT methodology my data source was already selected as was its boundary (coroners' reports on choking deaths in at-risk adults 2000-2010 which equated to 256 cases). I was using only one mode of knowing – coroners' reports – with no resource capacity to collect further data from additional sources in order to develop theory as it emerged. The volume of data I was already dealing with, the analysis already underway, and the practical impossibility of interviewing either at-risk adults before they choked and/or carers after a fatality, effectively tied me to the data I had.

It would be reasonable perhaps to present the argument that my failure to follow this basic tenet of GT voids my claim of having used GT for this study. I certainly had this argument with myself when considering GT as my methodology. On further and ongoing consideration however, a number of choices taken early on in my PhD journey I believe at least reflected the spirit of theoretical sampling if not its strict procedure. These choices were concerned with the possibility of reducing the amount of data I was trying to manage and analyse. The choices centred on only exploring the social

context of choking in assisted-care settings or in private settings or only considering the at-risk adult (ignoring the position of carers) or only analysing those choking deaths that went to a coroner's inquest.

Choosing to limit the data in any one of these ways would have reduced the analytical burden, however failing to have these different data slices (providing different views) to code and use for constant comparative analysis would have limited the exploration of the social context and the emergence of any theory of substance; much substantially and conceptually would have been lost. It is clear from Glaser's work that having outlined the elements which comprise classic grounded theory methodology he maintained that a study can only be considered true GT when all elements are utilised (Holton, 2008). I acknowledge this position, however I believe that having followed classic grounded theory methodology in all other respects in this study (and having been highly inclusive in my sampling technique), theoretical sufficiency was attained and a substantial theory did emerge.

As it stands, therefore, this study principally followed the conceptualisation and suggested method of the original methodology of classic GT. It presents a substantive theory of choking that incorporates previous theory on this topic but offers a new conceptualisation that includes the social context of choking, and by doing so highlights new ways of understanding and approaching care.

The following section illustrates the method I used to engage with and analyse the data and how the substantive theory of 'considered support' emerged from it.

SECTION 2: METHOD

The Data Source

The data source for this study was Australian coronial reports. Coronial reports are part of the investigative process into 'reportable' deaths performed by the coroner's court. All Australian states and territories have a coroner's court. Reportable deaths are determined by the *Coroners Act* in

each state or territory, but in general such a death meets one of more of the following criteria: the death was sudden and unexpected; the death occurred in care (generally custodial care such as a prison or mental health facility); or the cause of death could not be determined. Choking can meet all of these conditions and therefore is considered a reportable death (Freckelton & Ranson, 2006).

The coroner's court is a non-adversarial court. The key purpose of the court is to: determine the identity of the person who has died; the cause of their death; the circumstances surrounding their death; and if possible make recommendations to prevent future deaths (see Appendix 2 for an outline of coronial process). To this end a number of reports may be produced as part of an investigation. These reports may include:

- A police report (based on examining the scene and interviewing witnesses);
- A forensic pathology report (based on the performance of an autopsy);
- A toxicology report (outlining the presence and amount of any drugs or alcohol in the deceased's body);
- An inquest report (outlining the most extensive form of investigation which can include all of the above reports and a comprehensive summary of a formal court hearing into the death where the coroner hears witness statements which may also include expert testimony); and
- A finding without inquest report (where the coroner presents a finding on the death based on preliminary investigations).

Not all deaths will be fully investigated as this is at the coroner's discretion, and therefore not all deaths will have the full range of reports possible. Some inquest reports may be released into the public domain, again at the discretion of the presiding coroner (Freckelton & Ranson, 2006).

Access to the data source

Access to the data is through the National Coronial Information System (NCIS):

The **National Coronial Information System (NCIS)** is a data storage, retrieval, analysis, interpretation and dissemination system for coronial information. It enables coroners, their staff, public sector agencies, researchers and other agencies to access coronial data to inform death and injury prevention activities.

(National Coronial Information System, 2017a).

The NCIS is under the auspices of the Victorian Department of Justice and Regulation.

Researcher access to the NCIS online data requires approval from the Coroners Court of Victoria (CCOV) Research Committee and the Victorian Department of Justice Human Research Ethics Committee (JHREC). Two levels of access are possible; level one gives access to all data related to closed cases (including all available case reports) and level two gives access to non-identifying data. Level one access was required for this study; as a consequence additional approval was required from the Western Australian Coronial Ethics Committee and Coroner's Court of Victoria Research Committee.

Access to the NCIS is via password; authorized users (researcher and the organization supporting their research) are required to enter into an Access Agreement that governs the use of the data and user responsibilities (National Coronial Information System, 2017b).

Ethics

The proposal for this study required initial organisational endorsement from: The Tasmanian Department of Health & Human Services (the researcher's employer), the School of Medicine, University of Tasmania (the researcher's place of academic study), and the Tasmanian Justice Department (the initial conduit for access to the National Coronial Information System). Ethics

approval for the study was through the University of Tasmania Health and Medical Human Research Ethics Committee. Additional ethics approval was required to access Australian coronial reports from the National Coronial Information System (NCIS).

As discussed above, the National Coronial Information System is an electronic database that functions under the auspices of the Victorian Department of Justice and Regulation. Since 2000 it has been the depository for coronial reports from around Australia³³. While some coronial reports are in the public domain (at the discretion of the relevant state coroner) most are not. Access to coronial reports therefore requires approval by the NCIS and relevant Human Research Ethics Committees (HREC).

This study therefore required and received the following approvals:

1. National Coronial Information System (dependant on approval from the following – see Appendix 3 for approval letters)
2. Coroners Court of Victoria Research Committee (CCOV RC Ref:115)
3. Department of Justice & Regulation HREC (approves access to all data except WA data)(CF/12/1569:CF/15/10376)
4. Western Australia Coronial HREC (WA has an independent process for access to its coronial data even though the data is located within the NCIS data base) (Ref No: EC09/2012:EC19/2015)
5. University of Tasmania Health and Medical HREC (Ref No: H0012275)

The Study Sample

This study was specifically concerned with exploring the phenomenon of choking (foreign body obstructions) in adults who are potentially more at risk of choking than the general population due to the presence of or predisposition to swallowing and eating problems. The data sample therefore needed to capture choking fatalities related to foreign body obstructions (as

³³ Queensland data was included in the data base from 2001.

opposed to choking through other causes such as violence or trauma) and the particular population group of interest.

Initially, in order to capture the most comprehensive sample and one that would ultimately come to provide theoretical sufficiency, the parameters of date range and location (available in the search settings of the NCIS database) were arbitrarily set at 2000-2010, along with all Australian states and territories.

Identifying choking (foreign body obstructions) cases

To identify foreign body obstruction cases, on the advice of NCIS staff an electronic search of the NCIS data base was performed using the following available search parameters:

- 1) Date range 2000-2010
- 2) All states (included Australian territories)
- 3) Age > 18years
- 4) Mechanism: Threat to breathing - Mechanical Threat to Breathing - Obstruction of Airway by Inhaled Object/Substance

This search generated over 900 cases.

Identifying adults particularly at-risk of choking

The population of interest was adults who were clinically considered more at risk of choking than the general population. An increased risk of choking has been established in adults of advanced age (due to the presence or predisposition to dysphagia caused by normal ageing) and/or those with medical conditions associated with dysphagia (Cleary & Hopper, 2010; Dolkas et al., 2007; Ney et al., 2009; Sayre, 2005); the predisposition to or identified presence of dysphagia being the common feature of both groups. Advanced age (70 years or over) and/or relevant medical condition therefore were the primary criteria used to identify an 'at-risk adult'. Relevant medical

conditions were considered to be those with a known association³⁴ with swallowing and/or eating problems³⁵ such as motor neurone disease, stroke, and intellectual disability (Cichero & Murdoch, 2006).

There was no key search parameter that could be entered into the data base to extract the relevant cases for this study. The case reports for each of the choking deaths in the data search above (n>900 cases) were therefore individually read to determine relevance. There were five sources of information on the data base for each case:

1. Identification Panel.
(this panel outlines basic demographic information such as name, age, place of residence, but does not include medical information)
2. Police Report
3. Autopsy Report
4. Toxicology Report
5. Coroner's Finding (included inquest reports)

Each case was read to identify age and medical history. Those 70 and over were quickly identified using the identification panel. Relevant medical history however could appear exclusively in one of the four primary sources of information (as noted, the case identification panel did not include medical information) or be repeated across several of the sources. The Police Report was the first source read for each case. If medical history was not indicated in this source, then subsequent case reports were read to determine the presence or otherwise of a medical condition relevant to dysphagia.

Not all cases included a documented medical history. There were however, indicators in some case reports of relevance for inclusion in the study despite the absence of specific medical history information. In such reports the person was listed as residing in a form of medically assisted-care setting

³⁴ Swallowing and/or eating problems is listed as a symptom of the disease or its treatment, the condition is reported in the dysphagia literature, or the condition is represented on the clinical case load of adult acute or community public service speech pathologists.

³⁵ Eating problems in this study were defined as eating behaviours such as gorging, eating too fast, and/or consuming non-food items which could compromise swallowing function and or lead to choking.

such as a mental health facility or dementia unit, which indicated the likelihood of a relevant medical condition. In other cases the deceased was reported to have had swallowing problems or previous choking events prior to death.

The selection criteria for cases (the sample) in this study therefore became the following:

1. All cases where the deceased had an injury, illness or condition associated with the possibility of swallowing or disturbed eating behaviours, such as acquired brain injury, Parkinson's disease, cerebral palsy, or mental illness.
2. All cases where the deceased was 70 years or over (and not included under the first criterion).
3. All cases where swallowing or disturbed eating behaviours or previous choking events had been identified prior to death (may or may not have been included in the above criteria).

Challenges to case selection

All cases on the data base had an identification panel, however not all cases had reports attached. Reasons for this included: 'Not performed' (e.g. autopsy or toxicology); 'Not electronically available'; and 'Case dispensed no formal finding' (some reports may have been present). Some cases only had a police or a coroner's finding report which could consist of only a few lines of information. The absence of reports or the brevity of some meant there may have been cases relevant to this study which could not be identified as such.

Another challenge to case selection was the criteria used for study inclusion. The criterion of medical condition may have led to cases being included which did not meet the intended underlying focus on the 'at-risk adult'. Some medical conditions such as stroke or head injury may be generally associated with dysphagia, but depending on the site of the brain injury may not actually predispose or cause swallowing dysfunction. Such distinction is not possible given the degree of medical history collected for most coroners'

investigations. Some cases therefore may have been included in the study sample where technically the deceased could not have been considered as potentially 'at-risk' prior to fatally choking. This was a limitation of the study.

The final sample

After reading all foreign body obstruction cases, 256 cases met the study criteria of the deceased being an at-risk adult. Those cases which did not meet the criteria included choking due to self-harm, drug or alcohol overdoses, violence, and choking 'games'. Many of the over 900 cases originally identified were deaths due to drug or alcohol overdoses (choking on vomit) and cases of self-harm, rather than choking on food. If the death appeared to be due to non-food obstructions but the case met the study's criteria it was included, as the person was already vulnerable to choking because of a possible swallowing problem, regardless of additional vulnerabilities created such as excessive drug or alcohol intake and associated consequences.

Representing the data: Conventions

The primary data sources of this study were police, forensic pathology, inquest, and findings reports which are written as part of a coronial investigation. Excerpts from these reports will be used to represent the data throughout this study to illustrate particular points. When excerpts are used they will be followed by brackets inclosing the study case number and the type of report such as (002 Police report). Coroners' reports include a large amount of potentially identifying data such as the names of those involved (deceased, family members, staff, investigating police, presiding coroner, forensic pathologist) and dates, addresses, name of facilities and the state in which the death occurred.

Once relevant cases were identified, all potentially identifying data indicated above were removed. This information has been replaced with pseudonyms and/or general designators such as deceased, spouse, sibling, doctor, and personal carer. This approach is designed to protect privacy and

confidentiality, and aid readability while maintaining the integrity of the meaning of the excerpt. In addition, where descriptions of events may have elements that could make them more easily identifiable even with names excluded, gender or other elements may have been altered to further protect privacy but maintain contextual integrity; for example 'Huntington's' disease may be replaced with 'neurodegenerative' disease.

As the findings are being presented stylistically in a narrative format with coronial excerpts embedded, some additional conventions will be used to help readability. The researcher will use square brackets in excerpts [.....] to denote information which has been inserted to assist the reader, such as that which clarifies a technical term or provides contextual clarity. Also to aid the reader, occasionally the tense of excerpts may be altered or misspelt words corrected to enhance the flow of the narrative.

Analysis: Coding, comparison and memoing

Preliminary coding, comparison and memo writing

At this very preliminary stage of the study the techniques of grounded theory began to be applied. Case selection required the first cursory read through of not only the cases that would become this study sample but also the cases which were part of the broader cohort of those who choked – 'the general public'. While analysis had not "formally" begun, distinctions and similarities between the clinical group of those at-risk of choking being studied and other possible at-risk groups (for example, drug users) started to generate ideas which highlighted possible significant social phenomena such as setting, behaviour, and the presence of others. These impressions were notated for future reference. Preliminary coding had also begun within the data, initially via separating out 'those with medical conditions' and 'those over 70 without medical conditions'.

It is also perhaps worth noting here that it was probably the most emotionally draining and distressing time of the whole project for me as a 'researcher'; reading an overwhelming amount of data on over 900 deaths I could make

no claim to objectivity or distance from possible subjects, the circumstances of their deaths, or the distress their deaths caused others. Lives with all their complexity leapt from the pages, confirming the power of coronial reports to illuminate the social phenomenon of choking and bring the experiences of those involved 'alive'. While the task of selection had objective parameters, the first reading through of these cases was done mostly in tears and led to my personal reflection through memo writing, thinking and talking with others as to the breadth of an area which clinically I had previously considered 'just' one of the risks of dysphagia.

Organising the data and analysis

First level of organisation and coding

The initial read through of cases for sample selection had left me with a number of impressions. At-risk adults either lived in private residences or assisted-care settings, and where they lived influenced who might be a part of the social context of their choking. Assisted-care settings were defined in this study as any living situation (temporary or permanent) which included the presence of paid personnel who had an overall support or management role in regard to the at-risk adult. Personnel could be personal care assistants, disability workers, registered nurses, doctors or facility administrators.

The allocation of residential status for these two categories was not always straightforward. Where the person choked and who might be responsible for their care was used as a guide, reflecting informal support (family and friends) and formal support (paid carers as indicated above). Below are examples of decisions that were made when grouping cases, where the person could have potentially been placed in either accommodation group:

If the person was living in their own home and went into hospital to have an operation and while there choked; they were counted as being in an assisted-care setting i.e. the hospital.

If the person was living at home (private residence) and choked and was subsequently taken to hospital where they died shortly after; the case was counted in the

private residence group. This was because any contributing factors and the initial stages of any management would have taken place in the home context.

If the person was living in their home and received some home care this was counted as private residence as the paid carer was only present for short periods of time and had limited influence.

It was also noted at this point of analysis that these two contexts – private residence and assisted-care setting – seemed to have an influence on the coronial investigation process. In the 256 cases studied, no deaths occurring in a private residence proceeded to inquest. It was suspected at this stage in the analysis that there may be a greater expectation on formal, paid carers to provide a greater level of care than that expected of informal carers. I therefore decided to split the data into two, based on accommodation status. This splitting of the data not only allowed for greater ease in exploration of similarities and differences across the two types of environments (a dynamic contributing to constant comparative analysis) but also at a more fundamental level given the size of the sample, provided two distinct data sets which would support the grounded theory goal of theoretical sufficiency (Dey, 1999); allowing for the emergence of a theory that would broadly encompass both environmental and support scenarios and those potentially involved in the circumstances around choking events.

It was suggested early on in my doctoral candidature that my sample could be limited to just those cases that went to inquest. These 14 cases were more likely to have the full set of coronial investigation reports and lengthy additional data from the inquest proceedings. This would have been a sensible thing to do given the magnitude of data involved in analysing 256 cases. I was however (having already immersed myself in the data in my first study) loath to lose the rich data available in non-inquest cases (both those where the person was in private or assisted-care setting), so I proceeded with the 256 cases. In hindsight I do not believe I would have achieved the richness of data available in the larger data set had I only focused on inquest cases, let alone approached theoretical sufficiency, thus inquest cases and

non-inquest cases provided two additional data slices that could be compared and contrasted.

Second level of organisation and coding

The case reports being studied were by their nature often long descriptive narratives that tried to piece together what had happened. This narrative form had a natural underlying temporality: what happened before the choking event (documented in the police description of circumstances leading up to the event or the autopsy finding that identified the person's health prior to choking); what happened at the time of the event (witness reports or expert speculation); and what happened after the choking event (such as the at-risk person being placed on a ventilator or staff giving statements at an inquest). This temporal dimension was apparent across all cases (that is the original 900). It in effect equated to a 'beginning, middle and end' of an individual's choking account and provided a way of structuring the volume of the sample data and aided analysis. The allocation of data to one of the temporal sections drew out preliminary information and started to organise the data in a way that would shed light on the research question by highlighting the circumstances of each part of the choking story. Thus as all sample cases (256) and their available reports (police, autopsy, toxicology, inquest reports and coroner's findings) were read through in detail, data for each case were condensed, organised and coded under 4 major categories:

1. History of dysphagia and management

The data items under this heading related temporally to the beginning and middle of a person's choking story. Questions that emerged at this point included: Was there any indication of swallowing or eating problems prior to the fatal choking event? Had risks for choking been identified? These were questions that seemed to relate to the beginning of the story. Additional questions that seemed temporally relevant to the middle of the story included: Had a management plan or other strategies been put in place to address any risks identified? An overarching question was: Were there social circumstances that might have impacted on the answers to these questions?

This last question expanded the more traditional view of choking (where there are discrete risk factors that can/should be controlled) to consider the possibility of circumstances (environmental, behavioural, relational, emotional) related directly or indirectly to choking that were a part of the social experience of choking and potentially not controllable.

The next 2 organising categories pertained temporally to the end of an individual's story.

2. Physical signs (of obstruction) and identification

Questions which emerged from this category included: Why didn't everyone who choked react the same way? Did those present (victim and witnesses) recognise that choking was occurring? Were there social circumstances that influenced how choking manifested and was recognised?

3. Emergency response

Questions which emerged from this category encompassed: Who was involved? How did witnesses respond? Did first aid go as planned, and if not why not? Were there social circumstances that influenced how people responded? And finally: Were there social circumstances that influenced a death prevention approach?

The final organising category could relate to any of the stages in an individual's story.

4. Coroner's recommendations

This category organised specific coroner's comments and recommendations about an individual case. Questions which emerged from this category included: What did coroners identify as risk factors for choking? Did coroners solely align themselves with the management of risk? How did coroners respond to cases where risks were identified but not controlled? How did coroners' responses potentially influence the social context of choking? Table 1 illustrates how data were condensed and organised.

Table 3.1 Illustration of how information was organised and coded into four basic categories					
Comments code Red – history of dysphagia and its management Blue – physical signs/identification Green – emergency response Orange – coroner's recommendations Black - context descriptions/comments					
Column 1	2	3	4	5	6
Code*/ Available Reports	M/ F	Age	Medical history	Location/ Meal/ Food	Condensed, Summarised and Grouped Data** (D = deceased)
E.g. 111* P [police] F [finding] A [autopsy]	F	84	Dementia	ACF [aged care facility] Lunch	<ul style="list-style-type: none"> • Vitamised lunch being fed • D told not to eat any bread with food given to her [presumably bread in reach] • D “having trouble breathing”, D “jolted in her chair”, D was “blue in the face” • Heimlich attempted by RN but difficult to do as D a “dead weight” • Suctioned “small piece of bread removed from the D throat” • Placed on bed board advised by ambulance to “rub over the D ribs” no avail • CPR commenced • Ambulance arrived, airway contained fluid and a lump of ?meat in left posterior oro-pharynx Researcher Notes No specific indication why on pureed
112* P, F	M	81	Dementia	ACF	<ul style="list-style-type: none"> • Finding - choked on food • No further info
113 P	F	75	Parkinson's	Own home Snack peach	<ul style="list-style-type: none"> • Family report number of problems related to chewing food and restriction of airway, therefore D continually had trouble swallowing food • Evening, eating peach fallen to the floor and began to choke and stopped breathing • Family commenced CPR and called ambulance. On arrival amb. staff continued CPR. A second ambulance attended and removed a large piece of peach from D's trachea. • D then required defibrillation, was intubated, ventilated and transported to hospital. • On life support for 2 days, did not regain consciousness was not responding neurologically. Life support withdrawn with permission of family.
Illustrative only -some details changed for identity protection. *Each case received a unique numerical code so that the original de-identified case narrative could be returned to in future steps of the analysis and to extract evidence quotes as required. This returning to the narrative at different stages in analysis was an important check for the researcher to offset the dangers of condensing and summarizing information which could lead to relevant surrounding context being lost. ** Information available on each case varied significantly from essentially no information (e.g. ...choked on food) to lengthy reports. The above examples of data summaries are reflective of cases with limited or moderate amounts of information available. Some summaries of cases were several pages long and are not represented here. Coroners' recommendations were only present in some cases.					

General demographic information (gender, age, medical history, residential setting), time of choking, and type of obstructing foreign body were retained for each case. Previous research (Balandin et al., 2009; Berzlanovich et al., 2005; Bradway, 1996) had identified these factors may be relevant to the study of choking.

The allocating of data to the temporal sections, the questions that were generated as a result of this allocation and the sensitivity to the data which expanded as the questions were used to probe the data, all occurred simultaneously. Categories started to form, and as cases were organised in the above way each new case began to be scrutinised as either containing data that added to the tentative categories forming or suggested new categories. Memo writing included impressions of concrete categories such as 'behaviour' but also more abstract ones such as 'misconceptions', in addition to how some of the categories were linked. The following articulates this process in more detail.

Coding and categorising

Line by line coding and categorisation

The condensing and coding of data under the four headings (1. History of dysphagia and management; 2. Physical signs and identification; 3. Emergency response; and 4. Coroner's recommendations) was possible due to each report undergoing line by line coding. Line by line coding was used to categorise data under the four headings but also to identify categories within the temporal sections (beginning, middle, and end) of the choking experience.

The following example in Figure 3.1 shows how data extracts were identified and initially linked to possible issues; overall this data extract example belonged to the middle temporal section. Identifying data extracts was done while always considering the context and what possible abstract meaning was present based on the relationship between context and substantive data. The initial starting point to coding was the question: Is there any

phenomenon (physical and/or social) indicated in this sentence/excerpt that might either contribute to choking or be protective against choking occurring? Phenomena could be something discrete like 'the person gorging their food' or relational 'the carer providing supervision and doing a medicine round at the same time'. In this case the at-risk adult had cognitive problems, raising the question of whether such a factor may influence how accurately an at-risk adult can identify choking and their need for assistance.

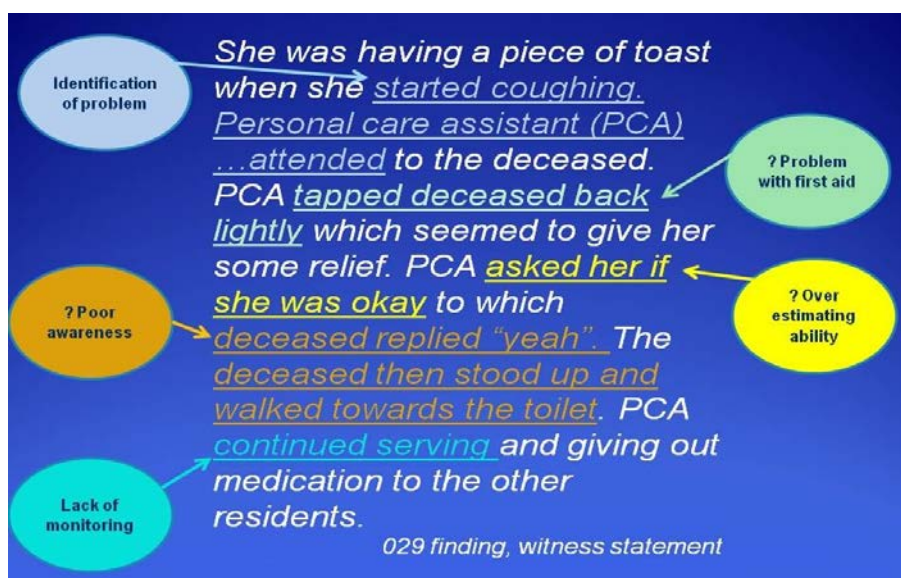


Figure 3.1: Example of coding data extracts

The at-risk adult in this case died from this choking event in the toilet. Possible categories produced from this coding included: 'identification of choking', 'first aid technique', 'victim awareness', and 'unexpected response'. As each new case was analysed these categories were either confirmed, expanded or collapsed into others.

Clarifying this analytic step further, and using the condensed examples given in Table 3.1, in Case 111: *D told not to eat any bread with food given to her* is a data extract, as is *Family commenced CPR and called ambulance* in Case 113 and *choked on food* in Case 112. Data extracts could be direct quotes from reports or a summary of a longer piece of narrative where non-relevant information had been excluded. A memo (context note) was attached to an

extract if the face value reading of the extract was distorted or diminished by the lack of contextual information.

Links and category formation started to happen simultaneously at this level of analysis. For example: *D told not to eat any bread with food given to her* I linked with the deceased's diagnosis of dementia (did the person understand the instruction?), which then lead to tentative categories including: person's behaviour (taking inappropriate food); faulty assumptions (carer assuming instruction would be understood and followed); training (carer not understanding cognitive deficits in people with dementia); lack of supervision; quality of life (person preferred bread to puree). In this study therefore a data extract could be placed in one or more initial categories, in keeping with constant comparative analysis of data and possible categories generated.

One possible flaw in this making of links and development of categories as illustrated in the bread example above was that I was speculating that the deceased person's dementia might be sufficiently advanced to impact on their understanding. This may not have been the situation. This possible problem was offset by constantly comparing data extracts across cases, seeking to confirm whether there were other examples of people with likely cognitive problems being expected to have awareness and self-monitor or manage their own behaviour. The at-risk adult in Case 029 (Figure 3.1) who reported being 'ok' and the at-risk adult in Case 111 (Table 3.1) who took bread against instruction therefore formed a possible pattern of communication and cognitive difficulties impacting on their risk of choking.

Challenges to analysis

Coronial reports are secondary data that have already been filtered through the perceptions of both those who were directly involved in the choking deaths and those charged with documenting and retelling key elements after the fatal event. Accuracy, detail and interpretation therefore may all be limitations inherent in the data and potentially additionally influenced by my own filters.

In the example: “...PCA tapped deceased back lightly which seemed to give her some relief” (Case 029, Figure 3.1). ‘Relief’ here could have entailed the person’s colour returning to normal, or her breathing becoming less constricted, or her facial expression relaxed or some other manifestation, but this information was not reported. Semantically, ‘tapped’ may equate with a ‘hit’ to some people. Lack of detailed information and different words could affect interpretation. Additionally, other than police investigations, which are the most immediate recording of events in coronial investigations, inquests and further questioning of witnesses may occur long after the actual event:

“I found the explanations given in court to be, on the whole, inconsistent with available independent evidence and unreliable. I accept on reflection this may be accounted for by elapse of time and contamination of the witnesses’ recall by concern and extensive cross-fertilisation and discussion brought about as part of the process of dealing with an unexpected death”

(009 Inquest – Coroner’s comment).

This delay in questioning may result in lapses of memory and reinterpretations of what occurred, on top of researcher interpretations.

However, constant comparative analysis over so many reports I believe diluted the impact of such possible interpretation errors. At face value ‘tap’, ‘rub’, ‘blow’ and ‘hit’ used to describe the application of first aid could have all meant the same thing, but by linking environment and the age of some at-risk adults and witness comments across different cases, it became apparent that these words overall reflected a genuine degree of difference in the degree of force applied from a first aid perspective. Some carers expressed concern that they would hurt the choking person; all such data comparisons aided analysis.

As the simultaneous identification of extracts and their coding occurred, multiple categories evolved, such as ‘at-risk adult’s behaviour’, ‘supervision’, or ‘communication/documentation’. These categories emerged over the course of analysing the data. Some categories collapsed into others. Sub-categories evolved and new broader categories were developed. These latter

categories started to become more overarching, as the concrete level of categories moved to the more conceptual level.

Theory: The tipping point between old and new theory

Emerging categories and becoming lost in old theory

At the most concrete (descriptive) level, the data and the categories it generated via analysis revealed specific issues, such as 'carers not knowing the signs of choking or how to apply the elements of first aid'. These issues had a direct relationship to choking risk and death. The resolution of these issues (basic choking first aid training) had potentially a direct relationship to the prevention of risk and fatality. Consistent with such logic, the providing of training to care staff to prevent future deaths was often a recommendation made by coroners.

A study focused on choking as a social phenomenon, and involving line by line coding and constant comparison across cases however, identified additional, more subtle, but still concrete issues. These issues clarified why carers might have trouble identifying the signs of choking (for example, the at-risk adult continuing to place food in their mouth while choking due to cognitive problems) or applying the elements of first aid (as in the case of the carer being not large or strong enough to apply a technique). Appendix 4 is an example of a memo which captures issues presenting in the data related to first aid. These issues initially formed 'a first aid knowledge category', but as more data were analysed this changed the category to 'first aid challenges', with 'first aid knowledge' becoming one of a number of sub-categories. Eventually the early category depicting challenges to first aid management would become linked with other descriptive categories such as 'dysphagia management challenges' and more abstract categories such as 'expectations and willingness', and finally find its place within one of the key overarching conceptual themes, that being 'awareness'.

Grounded in the data however, the 'first aid challenges' category was a highly complex one, containing content-rich sub-categories. The significance of these sub-categories was that they uncovered more risk factors for choking and more things that could be controlled for under a prevention theory. I present this example of the 'first aid challenges' category here to highlight several issues I encountered in the analysis in regard to sample saturation and the tension between verification of old theory and recognition of a new emerging theory; a trap identified by Glaser & Strauss in social research (Glaser & Strauss, 1967) when dealing with such a rich data source, a large sample, a health care area and an inexperienced researcher.

Glaser & Strauss's coding and constant comparative analysis ultimately proved a very elegant way of supporting the emergence of theory. However, along that journey to theory, these techniques also potentially uncover (as they did in this study) enormous amounts of significant concrete findings to the substantive area being studied, as with the 'first aid challenges category' example provided above. Initially this became a stumbling block in moving forward as concrete, practical information (which appealed to the clinician in me) pulled my focus from 'the bigger' picture of more abstract conceptualisation. At this more concrete level of categorisation the predominant theory of prevention and management through identification of risk factors and their control was not just being verified; new relevant data were being uncovered. As a researcher from an applied science background, this extraordinary influx of social data about risk and what more we could do to control it was incredibly seductive and I am not completely sure even now that I have broken its thrall. During analysis I experienced a very strong tension (not always conscious) between staying with the traditional theory and adding to it, versus continuing to analyse the data in the pursuit of new theory. This tension manifested in a great deal of confusion at times as I struggled with an enormous amount of data at different levels, none of which – because of its richness and value – I was willing to let go.

Consequently, three things became important methodologically to me as a researcher. The first was that I stayed the course. Secondly, that I

acknowledged that I was unlikely to be able to completely reject old theory for new given my background, and finally, any emerging theory would probably have space for or relevance to the old given how much of the data were linked to problems with prevention in the social context. I think this acknowledgement stopped me trying to unconsciously 'protect' the prevention-focused data and categories and left me open to seeing challenges to them, freeing me to distinguish new perspectives from the old. Specifically, in relation to the 'first aid challenges category', a focus on those issues that could not be resolved, such as speed of collapse, lead to an openness to explore and embrace in greater depth the place of death, both within individual stories and across stories.

Finally, to offset some of my concern in regard to my 'grounding' in the model of preventative care, I wanted to be able to identify at what point theory emerged in the analysis so that I could be sure I had not unconsciously fabricated a theory that inappropriately just supported the old one. I wanted to pin point as best I could where verifying and adding to old theory diverged into new theory. As discussed by Glaser and Strauss, this did not require a new method, but rather a continued persistence with the technique of constant comparative analysis and the use of negative examples until theory emerged (Glaser & Strauss, 1967).

Emergence of a new theory

There were two critical points in the constant comparative analysis – entailing looking for both similarities within and challenges to categories – where theory began to emerge in this study.

The first critical point was when the data and subsequent categories began to identify the 'reality' of death in the individual choking stories and across them. This may seem a 'given' as the data were coronial reports and the theory of prevention was focused on avoiding death. What emerged from the data however was the presence of social responses to the possibility or the actuality of death beyond the confines of avoidance. This more socially grounded data included such examples as: an at-risk adult deciding to risk

the possibility of death by choking for quality of life reasons; a husband finding his wife's dead body; a carer feeling responsible for a death when first aid did not work; or a daughter deciding to withdraw her mother from life support. It was for me as a researcher and clinician an illuminating moment, where basing choking management on a theory of prevention (which tried to create distance from death) left those involved unsupported when no distance was feasible. The data were demonstrating that a theory based on prevention, which attempted to avoid the possibility of death rather than embrace its possibility, was too narrow in light of the social context of choking.

The second critical point for theory emergence was when the temporal sections of all cases were analysed; that is, when the beginnings of all individual stories were compared and contrasted. When such a comparison took place a key conceptual category or theme was evident. Repeating this analysis for each temporal section uncovered that each section had a dominant theme. When each section's key theme was compared with one of the other sections it became apparent that each key theme was present in every section, but to a lesser or greater degree. These 3 key themes that were present across the whole temporal span of the choking narrative prompted the question: Was there an overarching conceptual theme that these three key themes 'fed' into; a core category or theme? If such a core category existed then it would form the basis of a theory that could encompass all the key themes, go beyond the prevention paradigm, and provide a workable framework for expanding choking management to better support both the at-risk adult and their carers across the environments of private and assisted care settings.

Such a core category and encompassing theory did emerge when the two critical points of realisation above were merged, crystallising a core category that brought together the three key categories. The theory that emerged was then checked against both the concrete and abstract categories identified in the data to assess its robustness. I judged the theory would be sound and robust if it could meet the following 3 criteria: Was there a place for all the

categories within the theory? Did the theory further understanding of the substantive area of choking? and: Did the theory provide direction conceptually and practically on how to understand and respond to the possibility of choking for at-risk adults and their carers? This assessment found that the core overarching category needed further illumination by way of a clarifying aspect or dimension, to allow for the theory to have practical application, either in part or as a whole. This clarifying dimension emerged from the data that questioned the quality and relevance of care provided across all three temporal sections. This core category of 'considered support' alluded to earlier in this chapter will be introduced in the following chapter and then further described and elucidated in Chapters 7 and 8 of this work.

Presentation of Results

As noted in Chapter 1, the aim of this study is: 'Exploring the social context of choking and its implications for care'. It was an enormous challenge to present the results in this study in a way that showed with clarity the complexity of the links and relationships between data and descriptive and conceptual categories. Initially there were a horrendous number of charts and tables trying to represent the different layers of analysis, the relationships between data and categories, the content of different categories, and the links between categories and how they all merged into theory. Unfortunately, rather than providing clarity they instead confirmed the multi-layered and relational complexity of the social context of choking. Driving home from a supervision session one day wondering if it were even possible to present the findings coherently inspiration struck, which I whimsically attribute to my deceased partners in this research whispering to me to 'tell our beginnings, our middles and our ends'. How could I refuse? Each of the at-risk adults in this study had a choking story; a story that was both theirs and their carers. Each story had a beginning, a middle, and an end. These stories were deconstructed and then reformed into categories following the tenets of GT, to enable the presentation of a theory that encompassed the social experience of living with choking risk. The best way I could honour those who contributed so much to this research and present that contribution is to let

anyone reading this thesis meet them. I have therefore in presenting the results taken elements from individual stories to create an overarching choking narrative in order to illuminate the social context of choking. A narrative which has a beginning, a middle, and an end. Not everyone's story could be told, but the excerpts presented in the following stories hopefully capture both the common threads between individual stories and their diversity.

The next chapter is the first of a series of four that present the findings of this study. As indicated, the findings are structured in a narrative format focusing on the beginning, middle and end of the social story of choking. Chapter 4 provides a brief introduction to the three key categories and core category that together form the basis of the theory of the social context of choking being offered in this study. It then offers a prologue to the choking narrative, setting the scene by providing background information on the medical challenges at-risk adults in this study were facing; where they lived, choked and died; and who else was a part of the social context of their choking.

CHAPTER 4: FINDINGS – SETTING THE SCENE

Preamble to the findings

The findings of this study are presented in a series of four chapters:

Chapter 4: The major categories and setting the scene

This first chapter provides a brief overview of the major themes, represented by 3 key categories and one overarching core category, which illuminate the social context of choking and together form the theory that emerged from this study. It then ‘sets the scene’ for what is to follow by providing background information on the social context of choking; describing the medical challenges at-risk adults in this study were facing and depicting the different settings where the social circumstances of choking may take place, including who may be involved.

Chapter 5, 6, & 7: The beginning, middle, and end of the choking narrative

The next three chapters present findings on the exploration of the social context of choking and show how major categories emerged from the data to illuminate an expanded theory of care. This is achieved by outlining a meta-narrative of choking which explicates its social context, presenting evidence for the emergence of three key categories and their dimensions and an overarching fourth core category that embodies the theory. The social context of choking is represented through the beginning, middle and end of individual choking stories which have been woven together to tell an overall story; the choking narrative.

Each element of the choking narrative – the beginning, middle and end – will highlight a particular key category. The final chapter ‘the end of the choking narrative’ will include a summary of what has been learnt about the social

context of choking and explore the theory elucidated by the data. The theory will be explained, highlighting how it helps makes sense of the social context of choking and illuminates an expanded approach to care that would support at-risk adults and those who care for them.

SECTION 1: INTRODUCTION TO THE MAJOR CATEGORIES

This section briefly introduces the 3 key categories (awareness, response, and acknowledgement) and the core category (support) that together form the basis for the theory that emerged from this study. These categories arose through the grounded theory methods of open coding and constant comparative analysis as outlined in Chapter 3. How these categories are conceptualised and how they will be demonstrated within the general findings is discussed. The theory will be addressed more fully at the conclusion of Chapter 7.

The emergence of a broader conceptualisation

A desire to provide care for those who may or do choke seems to be the common intention of studies on choking. As noted in the literature review, this care has historically focused on managing choking through a preventive or interventionist philosophical stance. This study explored the social phenomenon of choking and highlighted that choking care might require a broader conceptualisation in order to meet the needs of those affected by choking risk and fatality.

Preliminary coding of the data identified multiple substantive categories. As these categories were constantly compared and contrasted, they became integrated into new more abstract categories, culminating in three major, inter-connected categories: these being awareness, response and acknowledgement. These categories conceptually summarised the social context of choking. It became apparent via further inductive analysis of these categories using grounded theory methods (comparing and contrasting each

of the key categories with each other and testing for fit overall) that they had certain dimensions that could favourably (promoting wellbeing) or unfavourably affect how at-risk adults and carers experienced the social context of choking. These categories conceptually not only informed what was happening in the social context but also identified dimensions that could influence whether and how the needs of those involved in the social context of choking were addressed. The consideration of the key categories and their dimensions contributed to the identification of a core category. The following image reflects the process of how different levels of conceptualisation became evident, from the ground up:

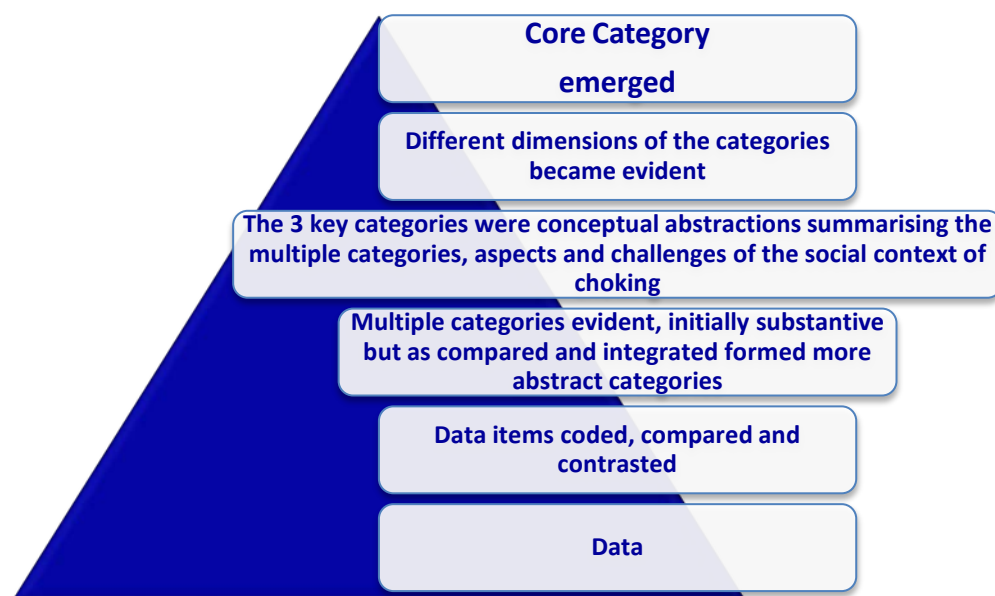


Figure 4.1: The different levels of conceptualisation

The three key categories: Awareness, Response, and Acknowledgement

Three key categories emerged from the data in this study as being significant to the social context of choking and potentially being significant to care. These key categories were: 'awareness', 'response', and 'acknowledgement'.

The categories, as conceptual representations of the data, are described in the following ways:

- ❖ The category of *awareness* means being actively alert or attentive to an area of concern and therefore primed to respond.
- ❖ The category of *response* refers to the engagement with a concern.
- ❖ The category of *acknowledgement* means the recognising and accepting of a concern.

As will be shown in the following chapters, 'a concern' may be broad or specific to choking and relate to diverse aspects such as choking risk factors or an at-risk adult's values or a carer's fear.

The core category: Support

The awareness, response and acknowledgement categories taken in total formed the core category of 'support'. The awareness of an area of concern, the responding to that concern, and the recognition and acknowledgement of facets of that concern taken collectively lead to the overarching concept of support. *Support* was chosen to characterise the core category in this study to capture the inter-relationship of the 3 key categories and how together they were more than the sum of their parts. The term was chosen to conceptualise this as it was felt to convey not only *the concept of aid or help but also the concept of holding up or sustaining*. The core category of support acknowledged that many people were involved in the social context of choking and affected by it, and therefore it was not only the at-risk adult who may need help and sustaining. Support can also encompass facilitating self-care. Support was also used conceptually to represent the core category

because of its broadness. The social context of choking as represented in this study did not preclude preventative and interventionist strategies or their philosophical dominance; such elements were present in many of the individual stories of choking. These elements are a significant part of the social context of choking; additionally, owing to its origins the data was potentially biased towards these elements. The coronial process partly explores a fatality from the perspective of what could have been done differently or what could be done differently in the future (Freckelton & Ranson, 2006) to prevent choking risk and possible death. The data collected as part of coronial investigations reflects this agenda and consequently slants towards management and control of risk and its expression. This management of risk and its expression is also aligned with the dominant clinical approach to choking care discussed in Chapters 1 and 2. Despite this possible prioritising of management and control, the data generated other elements of social concern which leant themselves to concepts other than control. Awareness, response and acknowledgment were not categories limited to managing and controlling. 'Support' therefore was a conceptual category that could embrace management and control but also other elements that fell outside those practices.

The four categories

The four categories as depicted in Figure 4.2 below therefore form the basis of a theory that could help make sense of the social context of choking and its implications for care.

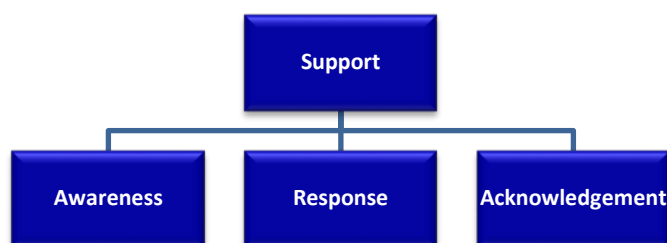


Figure 4.2: The study core and key conceptual categories

Illuminating the four categories

The overarching narrative of choking presented in the following chapters presents the data from which these conceptual categories emerged. Each of the key categories interweaves through the whole choking narrative to a greater or lesser degree, with each category being showcased in particular parts of the story: the beginning, middle, and end. The beginning of the story highlights the category of awareness, the middle the category of response, and the end the category of acknowledgement.

The data illuminates the social phenomena and challenges that clarify each of the key categories and by so doing identifies the different dimensions that underpin and support or challenge the expression of the category. The data also elucidates that there is a conceptual feature that is integral to all the categories when applied to the social context of choking; that being the qualifying feature of 'considered'. This feature will be discussed, in Chapter 7, as part of the *theory of considered support* that emerged in this study.

Awareness, response, acknowledgement, and their dimensions, along with the need for considered support is depicted in the following chapters that capture the social context of choking and its implications for care. To begin the exploration some of the background of the social context is highlighted to 'set the scene'.

SECTION 2: SETTING THE SCENE

This section presents findings that 'set the scene' for exploring the social context of choking. It describes the age and gender of at-risk adults in this study, the medical challenges they were facing and depicts the different settings in which choking took place and thus who may be involved in the social context of choking.

Demographics

Table 4.1 presents the age range of at-risk adults, their gender, and where they were residing.

The majority of participants (53 percent) can be seen to be aged over 70 years, and slightly more than 65 percent were resident in assisted-care settings. Males (53 percent) slightly outnumbered females in the sample.

Table 4.1 Age range and gender of at-risk adults and residential setting											
Residence	Age Range								Totals	Gender	
	18-29	30-39	40-49	50-59	60-69	70-79	80-89	90-99		M	F
Assisted-care setting	4	3	15	19	31	36	41	19	168 [65.6%]	91	77
Private residence	0	6	10	12	15	14	17	1	75 [29.2%]	37	38
Unknown	0	2		1	1	4	4	1	13 [5%]	9	4
Totals	4 [1.5%]	11 [4.3%]	25 [9.8%]	32 [12.5%]	47 [18.3%]	54 [21%]	62 [24.2%]	21 [8.2%]	256	137 [53%]	119 [47%]

Medical conditions and their implications

Table 4.2 presents the range of medical conditions/age associated with dysphagia represented in the study and the distribution of fatalities across the different conditions.

Medical condition profile

Most of the at-risk adults in this study were living with neurological medical conditions. Some of these conditions would have been present from birth, such as cerebral palsy or Down syndrome (MacDonald, Cockerell, Sander, & Shorvon, 2000). Other neurological conditions would have been acquired later in life. Of those acquired conditions, some were the result of one insult to the brain, with the long term effects potentially remaining stable after the acute phase, such as with a stroke or head injury (Mackay, Morgan, & Bernstein, 1999; Singh & Hamdy, 2006). Other conditions were degenerative in nature such as dementia, Parkinson's disease or motor neurone disease

(Altman, Richards, Goldberg, Frucht, & McCabe, 2013). Those with degenerative diseases would have experienced increasing physical and/or cognitive deterioration over time. Some adults with conditions such as mental illness or multiple sclerosis may have experienced exacerbations of their illness, with symptoms becoming worse and then perhaps stabilising for a while, or even improving depending on treatment (Aldridge & Taylor, 2012; Confavreux, Vukusic, Moreau, & Adeleine 2000). Those with inherited degenerative diseases may have watched the progression of their disease in family members. Some at-risk adults in this study had two or more medical conditions associated with dysphagia (one at-risk adult had a history of head injury, dementia, and throat cancer), further adding to the complexity of their medical profile and its possible impact on their day to day lives.

The particular medical condition, its severity, possible progression, and associated difficulties would have influenced the amount and type of medical intervention required, and the treatment strategies possible to overcome the risks and burdens of the illness (in addition to but aside from dysphagia). It would also have been a consideration in determining the amount of daily support the at-risk adult might need. Many doctors, specialists, allied health professionals and nursing staff would potentially have been involved in the assessment, treatment, management, and review of the person's medical condition and its symptoms. Daily support if required would most likely have been provided by informal (family/friends) or formal carers such as personal care assistants or nurses (Bodenheimer, Wagner, & Grumbach, 2002).

Table 4.2 No. of Choking Fatalities with Dysphagia Relevant Medical Conditions/Age Australia 2000 - 2010* (*Queensland data only available for 2001 - 2010)	
Medical Condition associated with dysphagia with typical onset and progression	No. of individuals with condition
(**neurological conditions)	
Combination Category (Person had two or more conditions associated with dysphagia) - In 69 cases at least one of the conditions was a neurological condition - Advanced age was not included in this category as a possible second condition associated with dysphagia - Conditions were a combination of congenital and acquired conditions, or multiple acquired conditions	72
Dementia** (acquired degenerative disease)	37
Mental Illness** (may be present in childhood, may become worse over time)	28
Intellectual Disability** (congenital condition)	12
CVA (stroke)** (acquired brain injury with the possibility of future strokes)	10
Parkinson's Disease** (acquired degenerative disease)	8
Head Injury** (acquired brain injury)	5
Cerebral Palsy** (congenital condition)	3
Autism Spectrum Disorder** (congenital condition)	3
Down Syndrome** (congenital condition)	2
Huntington's Disease** (Degenerative disease, onset of symptoms can be during childhood but most often in adulthood, usually hereditary)	2
Muscular Dystrophy** (Degenerative disease, onset of symptoms can be at birth, childhood or adulthood, usually hereditary)	2
Motor Neurone Disease** (acquired degenerative disease)	1
Multiple Sclerosis** (acquired degenerative disease)	1
Other - Single non-neurological conditions with a possible link to dysphagia such as oesophageal stricture, throat cancer.	7
Sub Total	193
Age >70 years	
70 years or over; no apparent relevant medical history for dysphagia recorded but the potential for presbyphagia³⁶	13
70 years or over; no details of medical history documented	41
Supplementary data	
Relevant medical history based on accommodation e.g. in mental health facility - Intellectual disability or mental illness (3) - Mental illness or dementia (1)	4
No medical history but dysphagia identified - One case long history of aspiration identified on autopsy	5
Sub Total	63
TOTAL	256
Summary 197 cases (77%) had medical conditions potentially associated with dysphagia 5 cases (2%) had dysphagia reported but no information on an associated medical condition 54 cases (21%) person 70 + with no relevant medical history or record but could have had presbyphagia	

³⁶ Presbyphagia: dysphagia associated with normal ageing.

Dysphagia profile

Depending on the medical condition, the severity of dysphagia and its impact could range from low to significant. Those with congenital problems may have had long-standing swallowing and eating problems. These problems may have been due to dysfunction of the swallowing mechanism, or abnormal eating behaviours due to cognitive deficits, or both. At-risk adults with congenital conditions may never have had 'normal' experiences with food; those who cared for them may have prepared their food, monitored food selection, and/or assisted them with eating and drinking. In contrast, those with acquired conditions (neurologically based or not) were likely to have had a normal range of eating experiences prior to their illness. These eating experiences would have included choosing food based on what they liked, disliked, or what they believed supported their health. They would also have had choices around how they liked their food prepared and presented and would likely have been independent in accessing food and been free to eat it when and where they wished.

Taking the above into account, some of the at-risk adults in this study would have always had dysphagia. Others with acquired medical conditions associated with swallowing problems, might never have previously experienced them (such as those with some types of stroke), or would have experienced them for a limited period (during the acute phase of their illness such as after a head injury). Some would potentially have had chronic swallowing problems, or swallowing problems that had become increasingly worse over time. Those of more advanced age might have experienced a slow change to their swallowing ability over time and consciously or unconsciously made adjustments to compensate.

Consequences

Except for those of 70 or over in good health (but with the possibility of age-related changes to their swallowing), most at-risk adults were living with long-term and/or life-limiting conditions. Many of the at-risk adults in this study would have been experiencing cognitive and/or physical difficulties on a daily

basis or facing their likelihood in the future. Swallowing problems and possible choking risk for most would have been one of many problems and risks associated with their medical condition. Due to their symptoms, disease progression, or the treatment strategies employed to manage it, many at-risk adults were potentially facing multiple burdens which might negatively impact on their quality of life. Their medical conditions and the difficulties that accompanied them would dictate how they lived, and for many would determine where and with whom they would live.

Where at-risk adults, lived, choked and died

Table 4.3 presents the findings on where at-risk adults in this study were residing when they choked, where they choked, and where they died.

Table 4.3 Where people lived, choked and died							
Where person was residing at time of choking event	Where people choked	Where people died					
(256 cases)		At place of residence	Hospital	Ambulance	Private residence	Public place/ Other	Unknown
Aged Care Facility							
91	86 [34%] at ACF 3 on outings 1 on visit to relative's home *1 waiting room	58 [22%]	16* [6%]	1		2 (restaurant) 1 (polyclinic)	13 [5%]
Mental Health							
Mental Health hospital: 2	1 at facility 1 on outing	1				1 (beach)	
Mental health unit/lodge: 13	13 [5%] at unit/lodge	8 [3%]	5 [1%]				
Psychiatric hostel: 1	1 at hostel	1					
Group Home							
4	4 [1%] at group home		4 [1%]				
Unclear Designation							
Hostel: 11	11 [4%] at hostel	7 [3%]	2			1 (restaurant)	1
Care facility: 10	9 [3%] at care facility 1 on outing	5 [2%]	2				3
Respite: 1	1 at respite	1					
Low care unit: 2	2 at unit		2				

Unspecified assisted-care: 16	15 [6%] at accom. 1 on outing	8 [3%]	5 [2%]	1			2
Residential lodge/service: 6	6 [2%] at lodge/service	5 [2%]	1				
Private Residence							
68	63 [25%] at own home 3 at home of adult child 2 at restaurants	49 [19%]	17 [7%]		1 (daughter's home)	1 (restaurant)	
Assumed Private Residence**							
5	3 at home 2 at restaurant		4 [1%]			1 (restaurant)	
Unknown							
13	1 in the bush 1 at boat mooring 1 at shopping centre 1 at sailing club 9 unknown		5 [2%]			4 [1%] (see where choked)	4 [1%]
Hospital							
Hospital: 13 Usual residence 1 from group home 1 from ACF 2 from private resid. 9 unknown	13 in hospital	(13)***	13				
TOTALS							
170 in Assist. care. (includes hospital) 73 at home 13 unknown	162 in assist. care 66 at home 19 on outings 9 unknown	156**** (107 assist. care & 49 priv.res)	76	2	1	11	23
<p>* Awaiting transport back to ACF after attending hospital for choking and thought to be stable ** Assumed at home from description of events *** If counting hospital as temporary place of residence at time of choking **** Total no. who choked and died at place of residence including those who choked and died in hospital (temporary residence)</p>							

Where at-risk adults lived

At-risk adults in this study were living in a range of different residential contexts when they fatally choked. Some were living in their own homes (n=73; 29%) with the majority living in some form of assisted-care setting (n=170; 66%) at the time of their deaths³⁷. Those living in private residences

³⁷ The residence of 13 (5%) of the at-risk adults in this study was unknown.

lived alone or with family or friends. Some of these adults received support from community based organisations that provided visits and in-home help. Those living in assisted-care settings resided in a variety of environments, but all of these were communal in nature.

Assisted-care options identified in this study included: mental health facilities, aged care facilities (ACF), group homes, respite units, hostels, lodges, low care facilities, and hospitals. These options varied in their composition; some were small with only a few residents and support staff, while others were large with many residents and staff. Several forms of accommodation, such as a mental health facility, provided specialist support for those with particular conditions. Some accommodation options provided short term stays, for example when the person spent time in a respite facility to give their family a hiatus from care responsibilities. Other accommodation options offered long term, permanent residency, such as ACFs.

The type and amount of support provided by each environment differed. The exact nature of support provided by these different environments was difficult to ascertain from coroners' reports due to lack of detail and the different accommodation labels used in different states, such as 'hostel' versus 'low care facility' versus 'lodge'. Case descriptions however, indicated that staff at the different facilities could range in number, composition and/or skill. Different staff roles represented in the cases studied included managers/co-ordinators, care assistants (personal carers, support workers), registered or enrolled nurses (RNs & ENs), catering and support staff, volunteers, and medical/allied health personnel (such as doctors, speech pathologists, dietitians).

Where at-risk adults choked

Contextually, where people choked was pertinent in regard to who might witness the choking event, their relationship to the at-risk adult and whether they could provide help. It also, as will be seen in the following chapters, influenced why at-risk adults might have choked in the first place.

The majority of at-risk adults choked where they resided – at home (n=66; 26%) or in assisted-care settings (n=162; 63%). Witnesses to choking events in this study ranged from no one if the person lived alone or was alone at the time, to family members, friends, personal care assistants, support workers, nursing staff, support staff, visitors at facilities, and other residents (if the at-risk adult were in an assisted-care setting). Additional witnesses included neighbours and medical staff, who although not present initially, were sufficiently close by to be called in to assist. When the at-risk adult choked in a public place, witnesses included restaurant staff and members of the public. In some cases in the latter instance, ‘members of the public’ included passing nurses and doctors.

Those most likely to witness choking events were family members, and care staff (personal assistants or nurses) or residents in assisted-care settings. Those witnessing a choking event could have no, basic, or advanced, first aid/life support knowledge. In this study, 13 (5%) at-risk adults choked and died while in hospital, where advanced medical and life support equipment was available.

Where at-risk adults died

Many at-risk adults died where they choked, that being at home or in assisted-care settings. This highlights that family or friends and paid carers (involved in the daily care of at-risk adults) were most likely to have to cope with witnessing a choking event, providing initial assistance, and watching someone they cared for die. They would also have had to potentially deal with the aftermath, which could include informing others, being questioned by police, and organising funeral arrangements around the complexities of an autopsy and other coronial processes.

If no one was present when the person choked, then family/friends, visiting care workers, or police completing welfare checks in the community were likely to be the ones to find the body of the deceased, potentially sometime after they had died. If the at-risk person choked while alone in an assisted-care setting, staff would be the most likely to find the deceased’s body. If the

person died in a public place then individuals without any connection to the at-risk adult may have to deal with death and the processes associated with it.

The findings also highlighted that some at-risk adults will not die where they choke; they will be transported to hospital where they will receive advanced life support. Their deaths, which will be explored in Chapter 7 which explores the end part of the choking narrative, will often not be quick (relative to dying at the scene). Such deaths may require someone, usually family members, to make decisions about ceasing treatments, including the withdrawal of life-prolonging interventions such as ventilation in the context of severe brain damage.

The next chapter will explore the social context of choking in more detail, outlining the beginning of the choking narrative and the key category of awareness. As part of this exploration, the category of awareness and its dimensions will be introduced in more detail.

CHAPTER 5: FINDINGS – THE BEGINNING

Three key categories or themes emerged from the exploration of the social context of choking. These themes were awareness, response and acknowledgement. These themes were evident throughout – the beginning, middle, and end – of the choking narrative, however the theme of awareness was particularly highlighted in the beginning of the narrative and therefore will be showcased in this chapter. The themes of response and acknowledgement will be showcased in subsequent chapters. This chapter is divided into two sections; the first section introduces the key category of awareness and the second presents the findings in the beginning of the choking narrative.

SECTION 1: INTRODUCING THE CATEGORY OF

AWARENESS

Awareness was critical to the beginning of individual choking stories and the choking narrative as a whole. 'Awareness' in this study is being defined as *being actively alert or attentive to an area of concern and therefore primed to respond*. It implies that there is a level of knowledge – an underlying understanding of the facts or particulars – related to a concern. Exploration of the social context of choking illuminated multiple areas of concern and many pieces of information that required acknowledgement and understanding for awareness to be possible. Lack of awareness or partial awareness of different concerns and their details was implicated in all parts of the choking narrative (the beginning, middle, and end) as negatively impacting on both at-risk adults and their informal and formal carers.

The contrast between people 'having', 'not having', or 'partially having' awareness illustrated that there were important dimensions to awareness that needed to be acknowledged and addressed, such as: who needed awareness; where awareness came from (how people gained information

about a concern); the kinds of awareness needed (factual, social, emotional); the level of awareness needed (general and/or specific to an individual); the breadth of awareness required (the ability to see connections between different concerns and their elements); how environment effected awareness; and how awareness was communicated to those who needed it.

The illustrative stories in the beginning of the choking narrative highlight the theme of awareness and its dimensions, while also presenting different aspects of the social context of choking – aspects that are at times distressing and confronting.

Preamble

Jo's, Glenys', Estelle's, and Stan's stories: The distress of choking

Jo

Jo choking, in his panic “...ran to the kitchen where he retrieved a large wooden spoon. Terry, a family member observed Jo stick the spoon down his throat in an apparent attempt to dislodge the piece of steak. This did not work.” Edith, Jo's wife “...tried to ring 000 however only said her address and then hung up.” Terry tried to help Jo; Edith “...in the meantime had contacted her daughter and sister....” Terry “...rang 000 and began following the operator's first aid instructions.” (120 Police report). Jo died at age 70; other than his age and the possibility of presbyphagia he had no medical history associated with swallowing problems. No risk had been foreseen, and as a consequence no precautions were in place. Jo was eating a steak dinner with his family. His choking story was brief. His death and the trauma of it however, may well have had a lasting effect on those who witnessed it. The panic that took place in both Jo and his family, and the need for support in a time of crisis, as illustrated by Edith calling her family, are strong elements of his story.

Glenys

Glenys, a personal carer, came to work not expecting that elements of her day would be recorded in a future coroner's report. Glenys was on duty with other personal carers when she was confronted with Maxina's (58 years old with frontal lobe dementia) choking: *"...Maxina's condition rapidly deteriorated...she started to turn blue...The personal care assistants recognised that she was choking. Glenys called an ambulance...There were no nurses on the premises that could be called upon to provide assistance [Nursing staff were not present on the weekend]..."* (024 Inquest). The following description from the inquest into Maxina's death describes some of Glenys' experience of the choking story: *"Personal care assistant was distraught – screaming at the call taker [ambulance call-centre] to help them...[Glenys]...stated 'I was panicking a little bit and the operator was trying to get me to calm down so I could explain what was going on'"* (024 Inquest). Another carer stepped in, taking over the communication with the ambulance call-centre; Glenys went outside to wait for the ambulance.

Estelle

"Choking events are distressing and frightening". "Choking would be a horrible way to die". These seem safe assumptions based on general perceptions of choking (Nuland, 1993, p. 160) and the introductory narrative fragments above. Such assumptions contribute to the desire to prevent choking at all cost. The experience of choking however, is not always what might be expected. Estelle, 85, walked down a corridor at the ACF where she lived: *"...she approached the two carers without saying anything or drawing particular attention to herself, other than the fact she was gazing at them. They observed her lips to start turning blue..."* (094 Inquest). Estelle's behaviour, while experiencing a severe obstruction of the airway, was the apparent antithesis of fear or distress, as was Stan's.

Stan

Stan, a 67 year old gentleman with a neurodegenerative disease, died eating his lunch on the couch in front of the television. Three of his family members *“...were eating in the dining room, one room away from where Stan was seated on the lounge. From where they were seated all three were able to visually see him from the dining room table”*. One of his family members noticed Stan *“...sitting upright on the lounge in the TV room with his eyes open. He approached him and sat next to him on the lounge to the left of Stan. Upon seating himself Stan has slouched to the right with his eyes still open, and his head drooped to the right” (108 Police report)*. The family member noticed Stan’s chest was not moving and checked for a pulse and was unable to find one. Outwardly, Stan did not appear to experience any distress; dying quickly and quietly in the company of his family. He and his family may or may not have considered his choking death a ‘horrible’ way to die. Those with a neurodegenerative disease, experiencing ever increasing loss of physical and mental function, may indeed view, within the context of their total experience, such an event as a ‘good death’.

Estelle’s lack of apparent awareness and distress at obstructing (perhaps due to cognitive difficulties) and the speed and lack of distress evident in Stan’s death, challenge the idea that choking events and death are always frightening and distressing, as appeared to be the case for Jo. An individual’s mental processing abilities and physiology are likely, be it positively or negatively, to affect an at-risk adult’s experience of choking. The experience of choking for those witnessing such events will, in addition to the particulars of the event itself, be influenced by both their personal connections with the victim, whether they feel confident or not to deal with the situation, and the outcome.

The above are small snapshots of some elements of the choking story; how someone might react to the experience of choking or the witnessing of it, and what a choking death might be like, its speed and other characteristics. These snapshots also hint at other elements of the story, such as the impact

of cognitive problems or lack of health professional support, as evident in Estelle's and Glenys' situations respectively. We now enter into a closer exploration of the choking narrative with already a hint of its possible complexity.

SECTION 2: THE BEGINNING OF THE CHOKING NARRATIVE

Introduction

The data used for this study were the coronial investigative reports gathered to address a choking death. The data come with a natural end point already built in; the review of an individual's death. Determining the end of the choking narrative may not be so easy to establish however. Multiple endings are suggested by individual stories. Mara, 51, suffering from a mental illness and living alone, was discovered by police completing a welfare check: *"...located laying on her back on the floor at the entrance to the kitchen...no signs of life...rigor...set in..."*(194 Finding). Alice, 86, who choked in a restaurant, had a different end to her story. She was *"...transferred to the Intensive care unit...did not respond favourably to treatment...After discussion with the family, it was decided to withdraw active treatment due to Alice's poor prognosis"* (247 Finding). For Maxina (024), whom we met in discussing her carer Glenys's distress above, was the conclusion of her story at the time of her death or when the findings of the inquest into her death were made public many months after her funeral? And does Alex's (62 years old with a mental illness and intellectual disability) story ever really end because a part of her story lives on in another, because as a result of choking: *"Brain death was declared and her condition did not improve and thus organ donation was carried out"* (103 Autopsy report).

A narrative, whether it is an individual's story or as in this study a collection of stories that were compared and integrated, traditionally has a beginning, middle and an end to its content and structure, albeit this is both an artificial

construct of how someone might perceive their life and by its nature potentially limiting of what is told in service of the 'story' (Barwell, 2009; Woods, 2011). Narrative is a common frame for coroners' reports as they aim to document a sequence of events in a logical order, and this narrative advantage and what it has to offer has been capitalised upon in other studies (Hurren & King, 2015). The social context of choking seems at times to defy the constraints of such order, but nevertheless a narrative framework is used in presenting the findings in this study to elucidate what happens around people living with choking risk. When the framework falters in its ability to portray that clearly, it can nonetheless serve to highlight the complexity of what happens – often simultaneously and in a non-linear way – in a social context.

A definitive beginning to the choking narrative is probably even more challenging to capture than a definitive end. For some like Jo, without any illness associated with dysphagia or history of difficulties with swallowing, his choking story, at least as captured in the coroner's documents, appeared to start moments before his airway became blocked and he reached for the wooden spoon. There was no evident pre-emptive awareness. The story for others however, might start long before their fatal choking incident. They might have a diagnosed or undiagnosed medical condition or be taking medication with side-effects that predispose them to increased risk. Some may have had eating or drinking problems or even choked previously, and the story of how they came to fatally choke might begin with whether their difficulties were identified or understood; whether there was awareness.

Not all possible beginnings will be illuminated in coroner's reports. Trying to discover the beginning of the narrative is however important for a number of interrelated reasons. The beginning of an individual's choking story may highlight what circumstances lead to a choking fatality and is therefore of relevance to the coroner in determining cause of death. From a prevention perspective, understanding how choking stories begin may provide insights into how to reduce risk and improve care in the future; making the beginning of the story particularly relevant to clinical care. While locating the beginning

of the story might be challenging because of multiple reasons including those mentioned, looking for possible factors that could indicate a predisposition to choking risk and whether that risk was acknowledged is a not unreasonable starting point. Given the chronological nature of coroners' documents, and while mindful of its limitations, it is the overarching frame used in this analysis.

Finding the beginning therefore, starts with exploring whether there were any indicators that the person was at risk of choking and if so, were these indicators identified and acknowledged. Jo did not appear to have any predisposing factors for choking. Stan however did, and his story most likely began when he first started experiencing the symptoms of Parkinson's disease; a disease associated with dysphagia and choking. Estelle had experienced choking prior to her fatal airway obstruction, but no action was taken to reduce her risk; the beginning of her story was overlooked by others. No warning, a predisposing medical condition, failure by carers to investigate an initial choking event; these are telling details in the choking narrative. The following accounts tell us more about the social phenomena surrounding the origins of choking in individual stories and their relationship to awareness; specifically, whether those involved were *actively alert or attentive to the concern of choking*.

In the beginning: Awareness of risk

All the individuals in the study sample died as a result of choking. They were all potentially at risk of choking because of advanced age and/or medical conditions associated with swallowing and/or eating problems. There was evidence that coronial investigators, particularly forensic pathologists, were aware of and acknowledged the connection between medical condition and choking risk:

"Death in this case is due to accidental choking owing to underlying Huntington's Disease, which is an expected fatal complication" (119 Autopsy report, Forensic pathologist).

"I find the deceased died from hypoxic brain injury due to aspiration of food. The cause of aspiration of food is directly linked to the eating problems deceased developed consequential of the progression of her frontal lobe dementia" (024 Coroner's finding).

"...people with intellectual disabilities are at higher risk of choking on food than other members of the community" (138 Autopsy report, Forensic pathologist).

Forensic pathologists have the advantage of hindsight. Risk can be amorphous; its degree and manifestations uncertain. Forensic pathologists are presented with the expression of risk as the outcome is fixed. They have the knowledge and skills to recognise predisposing and specific physical risk factors for choking and the analytical abilities to connect these risk factors with outcomes; they have the necessary awareness for their role. Forensic pathologists care for the dead. For those caring for the living and those who experience choking who are represented here, awareness of choking, the possible risk factors, the ability to judge degree of risk, and the capacity to see connections between risk factors was challenging. The following stories illustrate that what might be obvious in death may be far more subtle in life. Awareness has to come from somewhere; Geoffrey's and Anita's stories give some initial insights into who needs to have awareness and how they may come by it.

Geoffrey's and Anita's stories: The varying awareness of at-risk adults

Geoffrey

Geoffrey, 85, was aware he had problems around eating. He *"...was normally very careful when eating and ate mostly fish rather than red meat. This was apparently because he would have trouble swallowing and digesting this type of food"*. His daughter *"...states that when eating...her father...would often spit some of the food out into a handkerchief or similar if he began to experience difficulty in swallowing"* (068 Police report). Geoffrey, an elderly gentleman in failing health, had awareness of his problems and was able to use this knowledge to identify 'in the moment' when he was having specific difficulties

that increased risk; as a consequence he was able to take action (spit out the food) to minimise the potential for harm.

Anita

Anita, 58 with a history of brain injury, intellectual disability, and schizophrenia, did not appear to be aware of her difficulties. Her “...*normal eating habit would be to stuff her mouth full of food resulting in her constant choking*” (029 *Finding*). Anita, because of her acquired brain injury, was not able to identify that her disability (mental processing difficulties) and behaviour created risk. In addition to her cognitive problems she may also have had sensory problems which meant she did not physically feel that she was at risk, unlike Geoffrey who seemed particularly sensitive to his circumstances around eating. Regardless of the underlying cause of her apparent lack of awareness, Anita was reliant on others to be aware of her problems and identify their connection to her choking risk.

Even if an at-risk adult were aware that they were having difficulties, they may not be able to tell those caring for them. Medical conditions that can cause swallowing and eating problems may also be associated with communication difficulties. Clara and Maxina, whose stories will appear in more depth in the middle of the choking narrative, both experienced such difficulties. Clara (79 years old) “...*suffered a stroke which had badly affected her speech and ability to swallow food...*” (136 *Inquest*), while Maxina “...*was unable to effectively communicate, She did not speak*” (024 *Inquest*). If those supporting at-risk adults with cognitive, sensory or communication impairment do not have the necessary knowledge to identify risk, then such lack of awareness makes Anita, Clara and Maxina even more vulnerable. Awareness of choking and its risks, either of the at-risk adult or those who support them, does not automatically mean action to mitigate risk will follow, however lack of awareness makes the likelihood of such a response less likely.

At-risk adults may or may not have awareness about their swallowing problems and associated risks. If they have awareness they may not be able

to communicate that awareness to others. If they either cannot communicate or do not have that awareness, then they are heavily reliant on those around them. In such a scenario, carers need general knowledge about choking and its risks as well as specific knowledge about the at-risk adult's specific vulnerabilities to risk; they need awareness that is meaningful to their care role.

Phillip's and Clara's stories: The varying awareness of carers

The following stories alert us that carers, who might be expected to have awareness of choking (because of their roles and/or the environment in which they work), may not. They might not have the awareness or skills to recognise predisposing and specific factors that increase choking risk. If they do have knowledge it might be fragmented or they may have trouble making meaningful connections between risk factors.

Phillip

Eighty-year-old Phillip had dementia; struggling to care for himself, he was placed in hospital under a guardianship order. Nineteen days after his admission he was reported to be dehydrated due to poor oral intake; at the time he was on a normal ward diet (all food consistencies with no restrictions). The coroner's finding documented: *"A preliminary assessment was undertaken [by a Dietitian, 16 days after admission] however a full dietary assessment was not conducted due to higher priority patients"*. Three days later, 19 days after admission, Phillip was: *"Reported to be dehydrated...He was encouraged to drink fluids"*. On his 23rd day in hospital he was admitted to a ward with a higher staff-to-patient ratio and it was noted: *"Tolerating moderate amount of meal, needs to be fed. Slow chewing."* The next day a nursing note mid-afternoon recorded: *"...eating well but does not like chewing meat...Phillip would try a small amount but found it dry and tough. A further entry at 8.30pm records a small dietary intake, ?lack of teeth!! [question and exclamation marks part of nursing notes]."* A nurse had noticed Philip's poor dentition, however as the coroner noted: *"No change was made to the deceased's diet."* Phillip continued to receive a full ward diet

(no modification to compensate for his difficulties) and the next day he was served chicken for lunch, on which he choked and died. The forensic pathologist reported: *“Few remaining teeth in both upper and lower jaw were evident only as carious stumps. No dentures present”* (229 Finding).

Because of his illness, Phillip was reliant on others to help protect him from the risk of choking. In order to protect Phillip, his carers needed to be aware of the possibility of general and specific factors that increased risk. Dementia, dental inadequacy, and advanced age are all ‘known’ risk factors for choking (Cleary & Hopper, 2010; Kramarow et al., 2014; Mittleman & Wetli, 1982). But known by whom? When it was noticed that Phillip was having specific difficulties (namely slow to eat and chew; both likely related to his dental problems), these difficulties, combined with dementia and advanced age, did not appear to trigger sufficient concern to prompt further investigation or action beyond basic documentation.

Phillip’s story seems characterised by both a lack of awareness and a lack of appropriate action. Even when his poor dentition was identified there was no attempt to modify Phillip’s food to compensate for his difficulties or enhance his comfort or pleasure while eating. Lack of awareness, combined with a failure to identify and adequately investigate his physical problems, contributed to Phillip’s fatal choking. The social phenomena surrounding Phillip’s choking however were complex.

Phillip had been struggling to cope with the effects of his dementia; he was restless, agitated and violent at times. Staff would undoubtedly have been coping with Phillip’s multiple, complex needs. Resource constraints at the hospital made assessment of his eating and drinking (which might have enhanced awareness and knowledge) a low priority. The coroner found: *“...there was a failure by the hospital to undertake and document an appropriate dietary assessment of the deceased’s needs. Further, a failure by the hospital to accommodate his dietary needs [after documentation of lack of dentition]...resulted in the deceased dying from acute asphyxiation following the inhalation and impaction of a piece of meat on the back of his*

throat.” Without the overt identification of risk, there was no opportunity for management. In acknowledging the “...*regrettable lack of systematic policy to ensure an assessment occurred...*” following Phillip’s death, the hospital introduced a policy that stated: “...*patient’s first meal is observed by nursing staff and if any chewing/swallowing difficulties are observed the patient is referred for speech pathology assessment*” (229 Finding).

While the hospital’s attempt to prevent further choking deaths through a change in policy is admirable, the concern here is that Phillip was in hospital for 23 days before nursing staff either recognised he had chewing difficulties due to poor dentition or viewed such a lack of dentition as worthy of documentation. While staff would have been aware of his advanced age and severe dementia, they did not appear to link these predisposing factors for choking, along with the added risk of poor dentition. This suggests that care staff, even if they identify a problem with eating and drinking, may not understand its significance and potential fatal consequences.

If Phillip had been assessed by a speech pathologist (a representative of a profession with expertise in dysphagia care as discussed in Chapters 1 and 2), the factors contributing to his choking risk may have been identified and managed. This seems to be the hope behind the hospital’s new policy, which identifies the speech pathologist as having the knowledge needed to address Phillip’s risks. The anomaly in this logic however, is that nursing staff would be the identifiers of problems and risk in the new policy; in effect acting as the gatekeepers for referral. Phillip’s story would suggest that they lacked the necessary degree of knowledge to do this effectively.

Phillip’s story highlights a number of important dimensions to awareness: What awareness is needed? Who had the awareness? Who needed the awareness?

Phillip’s story suggests that lack of staff awareness and knowledge, and a consequent lack of appropriate action, were key elements in the beginning of his story. The hospital’s response to his story, both before and after his death, would also suggest that social elements such as hospital resources

and inadequate policies also impacted on Phillip's individual story. The presence of broader elements impacting on the beginning of choking stories is illuminated further in Clara's story below. Clara's circumstances differed from Phillip's, as there seemed to be awareness and knowledge that she was at risk, yet the identification of risk still went awry. A recognised missing element in Phillip's care, a speech pathology assessment, was a part of Clara's story.

Clara

Clara had suffered a stroke. Strokes potentially predispose people to swallowing problems and choking risk (Finestone et al., 1998). Clara's stroke had badly affected both her speech and ability to swallow food safely without choking. She was in a specialised Stroke Unit, where her problems with swallowing had been identified and assessed by a speech pathologist. In addition, there was a general dysphagia management protocol in place in the Unit, which required patients never to be left alone with food or drinks. Despite her dysphagia, Clara's risk of choking and fatality should have been minimised because of the apparently high level of awareness of her difficulties and their relationship to risk. Her story however illustrates that there may be different types and levels of awareness relevant to choking risk.

Clara had originally been prescribed a vitamised diet (all food pureed), but after a review by the speech pathologist she was reassessed to see if she could manage a soft TM diet meal (the requirement being that food is soft, moist and cut up into small pieces³⁸). Clara was however unable to manage food of this consistency. As she had failed to cope with the soft diet meal when she was re-assessed, she was prescribed a minced and moist diet (all food soft and moist, but minced, making the particle size of the food very small). A misunderstanding by kitchen staff however meant she was served a soft diet meal (instead of the required minced/moist meal) the night she died. The nurse on duty, having not checked the progress notes detailing which diet she was meant to be having, did not pick up the mistake and did not

³⁸ Pieces of approximately 1.5cm

identify at the time of eating that Clara could not cope with the meal due to her dysphagia. The nurse did however identify some risks which she addressed.

The coroner at inquest summarised the nurse's statement, illuminating the problem staff have in identifying all relevant factors that contribute to risk: *"...RN assisted by sitting deceased up".* There appeared to be an awareness that Clara needed to sit upright to eat safely, showing an identification or knowledge of the risk of poor positioning. *"Evidently the deceased then attempted to feed herself but RN could see that she was having difficulty. RN told me [the coroner] that she cut the chicken off the bone into bite-size pieces so that all deceased had to do was pick it up with the fork and feed herself. RN told me that the deceased appeared to cope with this".* The RN identified that Clara was having manual difficulties cutting the food which she addressed, but failed to see other difficulties associated with the actual eating of the meal, such as Clara placing large amounts of food on her fork, pocketing food in her cheek, and failing to swallow food placed on the paralysed side of her mouth, which were characteristics which made it unsafe for her to eat a soft diet and which had been earlier identified by the speech pathologist. *"RN then left the deceased; I take it alone to perform other duties"* (136 Inquest, coroner's summary).

Clara was receiving care in a designated Stroke Unit where one might expect a high degree of awareness of the common problems of stroke such as dysphagia and its possible consequences. Unlike Phillip, Clara's difficulties had been identified and assessed by a speech pathologist and were being regularly reviewed. Communication strategies (progress notes) and protocols (not leaving the person alone with food) were in place to assist in raising and maintaining awareness of problems. Clara was reliant on her carer being aware of the importance of being informed and following protocols. She also needed her carer to be aware of not just general risk (theoretical awareness) but to be able to identify specific factors (practical awareness) that put her at risk in the moment.

Clara's story serves to illuminate that awareness of problems and risk could not be superficial (a general knowing that the person had problems and was at risk); awareness had to be grounded in everyday events and an understanding that risk might be created by a web of factors, not just one factor at any one meal. If swallowing problems and their risks were not recognised and monitored at every meal the consequences could be fatal, as they proved in Clara's case. Awareness needed to be ongoing and adjust to changing conditions.

Clara's attending RN did recognise some risks, namely that Clara likely had difficulties cutting up food and positioning herself effectively for eating because of her stroke. However some awareness was not enough; Clara's RN needed more in-depth knowledge. Acknowledging this, the coroner recommended: *"...that the hospital ensure that nursing staff, who are caring for patients with swallowing disorders, fully understand the risk factors associated with the individual patients in their care so as to enable them to more readily identify situations in which a patient has been provided with a meal of inappropriate consistency"* (136 Inquest, coroner's recommendation).

Embedded in the coroner's comment that nursing staff should *"...fully understand the risk factors..."* are perhaps two more dimensions necessary for awareness; that awareness is considered of value and is dynamic, in order that carers be alert to new knowledge about concerns that may arise. The RN did not read the progress notes, which formed part of the communication protocol to ensure up to date information was integrated into awareness. If she had she would have been aware that the meal she served Clara was not the recommended texture for her safety, but the environment also impacted on awareness: *"Lack of time and opportunity was one reason advanced in justification of this attitude. The notion expressed in this Inquest that perhaps nursing staff should actually read the progress notes at the beginning of a new shift was treated almost as if the suggestion bordered on the heretical. I was not impressed by this attitude"* (136 Inquest, coroner's comments).

The coroner also noted: *“The evidence demonstrated that there is a widespread perception among the nursing staff in this ward that there is no need to consult the progress notes at the commencement of a shift, but rather to rely on the verbal handover and the handover board”* (136 Inquest). Seemingly, nursing staff were not abandoning the need for awareness but were rejecting the recommended communication channel. Using verbal handover and a summary board put awareness potentially at the mercy of a reporting staff member’s memory or their perception of the importance of multiple pieces of information. The poor awareness present in Clara’s story was not just about specific issues related to choking (identifying risk factors) but more general concerns related to the importance of documentation following processes and time constraints.

The expectation that nursing staff or indeed any staff have the requisite depth of knowledge and associated skill-set to recognise difficulties that could lead to choking may be ill-founded and an underlying issue in many people’s stories. Swallowing problems are a primary risk for choking, but their relationship to this can be complex and can include physiological issues such as a slow swallow reflex in combination with how a person is being fed. Difficulties may not be as obvious or as easily identifiable as missing teeth and may be very dependent on other aspects of social phenomena present at the time. An awareness of risk alone may not mean that a carer can practically identify all the facets of risk and address them. Clara’s story illustrates some of the important dimensions of awareness, including: depth of understanding of an area of concern appropriate to the role being performed; understanding of other bodies of knowledge (such as communication systems) which impact on the area of concern; attentiveness to how such bodies of knowledge inter-relate; updating and maintaining awareness; and a valuing of awareness.

In Clara’s situation there were safeguards in place so that risks such as her stroke and swallowing problems which were potentially heralding the beginning of a choking story were identified and acted on. Expert knowledge was available and communication strategies and protocols were in place for

conveying that theoretical knowledge. But Clara's choking story progressed because of breakdowns in communication, which started with the kitchen staff misunderstanding that they were supplying her with one soft meal for testing only, and not changing her ongoing diet to a soft consistency. Sadly, this initial misunderstanding was compounded by additional communication breakdowns, namely the nurse both ignoring protocol and not identifying that eating problems can be both manually- (cutting up food) and orally- (processing food in the mouth) based.

Awareness of choking and identification of risk (which may represent the fork in the road as to whether someone has a choking story or not), requires the person or their carers to have knowledge of predisposing and specific risk factors. Knowledge of factors alone however, may not be enough if connections are not made between related elements. Phillip's nurses did not connect (at least initially) his slow eating and dislike of chewing meat with his lack of teeth. They were also not aware of or did not link his poor dentition and dementia to an increased risk for choking. Unable to identify risk using their own knowledge base, staff were dependent on communication channels which passed on the knowledge from those with the requisite expertise. Channels for communicating necessary knowledge (such as protocols, risk factors, and food orders) had to be both accessible to the people relying on them, acknowledged as important by those people, and effective in conveying the correct information.

These elements that influenced awareness were present in and played a part to varying degrees in both Phillip's and Clara's stories. Gus's and James's stories take us deeper into the dimensions of awareness, particularly the dimension of communication, and illuminate how these impact on the beginning of individual stories and the choking narrative as a whole. In the next accounts there is the opportunity to view choking stories not just from the perspective of the person who chokes but also from the perspective of others intimately involved. Gus and James were paid carers who, because of their involvement with Barry and Angus, have their own personal choking story; a story which includes the death of someone they were caring for and

subsequently having their care questioned by those in authority (the police and coroner).

The choking stories of Gus, a personal carer and James, an RN, outline difficulties they had in caring for their clients, Barry and Angus, because awareness was not communicated by those who had it. Barry and Angus both had dementia, and were residing in ACFs.

Gus's and James' stories: Awareness and how it is shared

Gus and Barry

Gus worked for an agency that provided casual staff to assisted-care settings and was assigned to the facility where Barry, 77, with a diagnosis of dementia, Parkinson's disease and stroke, resided. Gus was *"not aware of Barry's propensity to place things in his mouth. He did not refer to the care plan and gave evidence that it was not compulsory for agency carers such as he was to look at the care plan"* (159 *Inquest*). Barry had trouble with oral dribbling. There were handkerchiefs in Barry's wardrobe which Gus assumed he was allowed to give to Barry. Barry choked and died after placing the handkerchief down his throat. Even had Gus checked Barry's care plan, it would not have provided him with sufficient awareness of risk, as there was no warning in relation to Barry's propensity for putting non-food items in his mouth. *"The only reference to his habit of placing things in his mouth appears under the part of the care plan dealing with dietary and nutrition issues... 'Explain meal times to Barry. Do not leave any food within Barry's reach as he will put everything in his mouth'"*.

The following information was provided at the inquest: *"In general permanent staff knew Barry had a habit of putting things in his mouth and that small objects should be kept away from him. For example buttons were removed from his clothing."* Gus was not a permanent staff member, however both he and other agency staff were regularly employed by the facility. There was no formal documentation of Barry's propensities, rather it was just 'known': *"...the systems at the nursing home failed in that handkerchiefs, which were*

apparently thought by many permanent staff of the Home to be inappropriate for Barry were nevertheless stored in his wardrobe. There was therefore an ever-present risk that an agency carer might assume that Barry could be provided with a handkerchief, particularly given his propensity for dribbling". Gus was not privy to the informal communication channels that permanent staff had access to with regard to Barry's care. In addition, the presence of the handkerchiefs in the wardrobe would likely have communicated the acceptability of their use to a naïve carer. The beginning of Gus's choking story began because others had failed to adequately communicate the beginning of Barry's story; his choking risk due to placing objects in his mouth. Awareness belonged to a group who were 'in the know', which owing to his status (an agency worker) Gus was excluded from.

James and Angus

James, an RN, had been transferred to night shift. He had previously worked on day shifts where there were protocols in place so that patients received the food consistency recommended by the speech pathologist; however the protocols were different at night. James gave Angus, 84 years old with dementia, a sandwich, which was against his recommended diet. The coroner noted: *"...given the accepted importance of diet and of eating/swallowing issues for patients in the ward I find RN's professed unfamiliarity with the overall system for ensuring appropriate dietary intake, both surprising and concerning."* Although James was deemed to have failed in some of his responsibilities, the coroner summarised some of the knowledge and communication deficits which contributed to his failure to identify risk: *"In fairness to RN [James] this unfamiliarity [with procedures around texture modified diets] may be a gap in competence attributable to his overall training at the special care unit and/or supervision, and/or may be attributable to the lack of appropriate orientation in night shift responsibilities, especially as to diet...I note that RN was not challenged about his evidence that he asked for just such orientation before working night shift, but none was provided"* (026 Finding).

Gus and James needed to understand Barry's and Angus's individual vulnerabilities around choking. This understanding was hampered by a lack of knowledge of the context in which they were working. Gus did not have access to information as he was neither part of formal (care plan) communication channels nor informal ones ('general' knowledge of Barry's risk behaviour). James was both unfamiliar with how care and risk was managed on different shifts and not provided with the orientation he requested. The required knowledge was held by some staff but not effectively communicated to all within the organisational contexts in which Gus and James worked. These problems were part of Gus's and James's professional choking stories and Barry's and Angus's personal choking stories.

Gus's and James's stories also suggest that others (management, other staff members) needed to have an awareness of Gus's and James' needs. As carers, Gus and James had needs for information and orientation that needed to be fulfilled so they could provide care to Barry and Angus. Here, different bodies of knowledge (awareness of risk factors and awareness of how the environment works) were needed to create meaningful awareness. It also highlights that particularly in assisted-care settings, awareness needs to be present at different levels (such as direct care and managerial). Communication across and within different levels becomes an intrinsic dimension of awareness. Such communication is only possible where there is an awareness of who has knowledge and the need for that knowledge to be passed on to those who need it. Simon's and Janice's stories demonstrate that a choking story might begin when the keepers of knowledge relevant to choking are not acknowledged and their input not sought.

Simon's and Janice's stories: Identifying the keepers of knowledge

Simon

There was limited information relating to Simon's story, as only the police and autopsy reports were available. However what is known is that Simon was in his eighties, had dementia, heart problems and depression, and a history of stroke. Based on his multiple conditions and their potential for swallowing

difficulties it was likely he was at risk for choking; a risk that his family had seen expressed: *“Upon speaking to the next of kin (NOK) at the scene police found out that the deceased for a period of about 9 years leading up to him being admitted to the nursing home, frequently choked while eating. Sometimes to the point where he would pass out due to the lack of oxygen. The NOK also stated that due to the deceased suffering from dementia, this resulted in the deceased over eating to the extent of choking. He did not know when to stop. The Director of Nursing stated to police that this information was not passed onto her or other staff members. She stated the deceased would feed himself however it was supervised” (083 Police report).* We do not know how long Simon had been at the ACF nor do we know if he had been assessed for swallowing problems while at the facility, although if he had been it seems unlikely that the director of nursing would not have reported this to police. At the time of choking Simon was eating his breakfast, which consisted of toast, cornflakes, fresh fruit, and scrambled eggs; a range of different food consistencies that could potentially increase risk for someone with a choking history.

Simon’s story highlights not only communication problems but also the potential for awareness to become lost across formal and informal carers. Simon’s family had knowledge of his risks (the beginning of his choking story), but reportedly they were not passed on. His swallowing and eating behaviours were reportedly significant and overt, but the director of nursing seemed to imply that because the information had not been passed on neither she nor her staff were aware of them. Supervision was provided, however as previous stories have demonstrated, without staff awareness identification and reduction of risk factors may not have occurred. Simon’s family held knowledge that others did not have. Expectations and assumptions may impact on the sharing of awareness across different carer roles and environments. Simon’s family may have expected formal carers to have certain levels of knowledge, while formal carers may have assumed that family would have told them if there were problems. Janice’s story seems to tell of similar issues relating to awareness: Who has it? Who needs

it? How is it obtained? In this story the coroner outlined how awareness should be managed in the future, albeit sadly too late for Janice and her husband.

Janice

Janice normally lived at home with her husband who was her full-time carer. 67 years old and diagnosed with Alzheimer's disease, she could not feed, bathe, or clothe herself. To give her husband a break from his caring role, Janice was admitted to a dementia care facility for a short respite stay. She fatally choked at her first meal in the dementia facility. The coroner presiding over her case made a number of recommendations related to overcoming awareness shortcomings and influencing communication problems, which he felt were connected to her death: *"Sufficient uninterrupted time should be allocated to the admission process to enable staff to obtain comprehensive instructions about the patient's needs from family/carer; a clinical risk assessment should be conducted of all respite [short term] patients at the time of, or proximate to their admission to respite centre including a specific assessment of their swallowing ability. Any risks and procedures to minimise those risks should be updated on the patient's file at time of each admission; the file should be read by the staff member conducting the admission prior to the scheduled admission; information about the patient's condition together with any risk minimisation measures to be implemented must be communicated to relevant staff in the most appropriate manner prior to any interaction they have with the patient"* (088 Finding).

Janice's coroner was addressing many of the problems that seemed to impact on awareness in the beginning of the choking narrative, and providing a remedy to building the necessary awareness. But the remedy was based on high expectations; that staff would be able to perform a clinical risk assessment and assessment of swallowing ability, and also identify risks and create and evaluate procedures to minimise those risks. The remedy as outlined represented a comprehensive response to the problems encountered in Janice's story but was also highly sophisticated; predicated

on a significant degree of awareness (knowledge and skill) on which to draw. The beginning of the choking narrative showed that carers often did not have this knowledge, thereby limiting awareness.

The source of awareness

Inherent in the stories of fatal choking explored is an underlying expectation, of both organisations and coroners, that staff 'would' or 'should' have awareness of concerns they were dealing with; that they would have the necessary background knowledge to be able to identify swallowing and eating problems, along with associated risks for choking. However, this expectation does not appear to be well founded. Staff did not demonstrate such awareness or else it was limited. If formal carers (care assistants and nursing staff) as a group or individually do not have the relevant knowledge and skills, the ability to access such knowledge may not be possible if they or their organisations are unaware that there is a knowledge deficit. Dysphagia and its relationship to choking is complex, and the identification and control of risk factors requires substantial knowledge and the ability to make relevant connections.

There was evidence in the data that some assisted-care settings acknowledged that speech pathologists had the necessary knowledge base required for general and specific awareness. Problems and risks can be positively identified by speech pathologists as dysphagia care is a core part of their knowledge base, but in this study only 10 of the 256 at-risk adults had reportedly been assessed by one (speech pathologists may have been involved historically with other at-risk adults but not documented). The involvement of a speech pathologist does not guarantee prevention of death, but their knowledge could inform and encourage awareness in both at-risk adults and their carers.

According to the data in this study, in the period leading up to their death, the identifying and monitoring of risk factors for dysphagia and choking lay with the person themselves or their daily carers in 96 percent (n=246) of the analysed stories. The stories represented here were from deceased

individuals (n=256) who were potentially more at risk of choking than the general public because of illnesses or conditions (including advanced age) associated with dysphagia. Under a third (32%, n=83) were documented as having been identified as having swallowing, eating, or choking problems prior to their death. Such identifying and monitoring lay with carers who had varying levels of awareness.

Level of awareness is a critical dimension, as is access to the knowledge base required for making meaningful awareness possible. For some, such as the forensic scientists and speech pathologists involved in the choking narrative, they have high level knowledge and awareness by virtue of their professional training. For these professionally prepared groups it is reasonable to assume a high degree of awareness, however these professions are also characterised by their relative distance from the experience of choking, being involved in post-mortem investigation or episodic assessment of those at choking risk respectively. Exploring the social context of choking uncovers that awareness may be assumed but not present in those more proximally associated with the choking event such as carers, to both their detriment and that of at-risk adults. In contrast, awareness may also simply not be possible. Mimi was living her life without any apparent need for awareness of the risks of swallowing problems.

Mimi's story: Awareness is not always possible

Mimi

Mimi was 43, living with an intellectual disability attributed to hypoxia at birth. She lived with her brother who also had an intellectual disability. Naomi, Mimi's friend and carer of 20 years, who assisted the siblings at home with the tasks of daily living, including preparing meals and eating with them, reported to police at the time of Mimi's death that Mimi had no medical conditions. Mimi was in good health and rarely saw the doctor; when she did it was usually only for flu shots. Mimi had no reported swallowing problems or difficulties with eating. On autopsy however, there was physical evidence of swallowing difficulties (evidence of previous aspiration in the lungs) and its

likely cause: “...myotonic dystrophy type 1 can cause weakness in the muscles responsible for swallowing and protection of the upper airway which then may predispose to acute and/or recurrent aspiration...” Mimi had “...muscle wasting and asymmetry involving the neck, trunk and proximal limb muscles. The fact that the core muscles of the body were affected suggests extensive and severe disease” (209 Autopsy). Mimi’s neighbour of 21 years reported to police: “I do hear coughing a lot” which was possibly a sign of her swallowing difficulties; a connection made only in hindsight. Mimi’s story could be further proof of lack of awareness in herself or those around her, but if so it is also an indicator that awareness has its limits. Mimi was living her life not in a clinical context but an overtly social one. The beginning of her choking story might have been at birth with a hereditary disease that later in life would put her at risk of choking or it might have only begun when she fatally choked.

CONCLUSION

Awareness was a key theme in the beginning of the choking narrative. Some at-risk adults and their informal and formal carers had an awareness of choking risk, however others did not. In the social context carers often did not possess the requisite knowledge for awareness. Necessary information included how to identify the signs of dysphagia and other risk factors for choking, knowledge of strategies to manage both dysphagia and choking risk, and for formal carers an understanding of processes used to identify and manage risk in assisted-care settings. In addition to needing relevant information, the complex interplay between the social context and conditions such as dysphagia, choking, cognitive and communication problems meant carers needed to make connections between different pieces of information. This ability to be aware of diverse areas of knowledge and merge them successfully into an appropriate level of awareness was difficult for many. Speech pathologists, who were acknowledged in some stories as having the necessary knowledge to support both at-risk adults and carers, were rarely present in the social context of choking. A central finding in exploring the

social context was how full it was of daily events, people, and competing concerns and as such, a constant awareness of choking risk may not be possible given the presence of other risks and the multiple demands of 'life' made on at-risk adults and carers alike.

In the social context of choking, informal and formal carers did not necessarily have the breadth of knowledge required to identify the conditions that created choking risk and choking events. Awareness may not always be possible in the social context, but attempts to address lack of awareness in the provision of care would need to consider the following dimensions based on the stories explored:

- What kind of awareness (general or specific) is needed?
- Who needs awareness?
- What knowledge is needed to inform and build awareness?
- Who has the necessary knowledge?
- How do those lacking awareness access the necessary knowledge?
- How is awareness communicated to all those involved in care (including the at-risk adult)?
- How can awareness remain current in changing social circumstances?

The theme of awareness is present throughout the choking narrative. The next chapter explores the middle of the choking story, showcasing the second key theme in the social context of choking: response. Awareness and response were intimately linked, with favourable (promoting wellbeing) or unfavourable responses heavily influenced by the level of awareness present. The beginning of the choking narrative had a natural focus on whether choking risk was identified; the middle of the narrative explored what happened next, focusing on – if choking risk was identified – what responses followed.

CHAPTER 6: FINDINGS – THE MIDDLE

The middle of the choking narrative showcases the key category of response. Awareness as the key category which emerged in the beginning of the narrative, discussed in Chapter 5, continues as a theme throughout the middle of the narrative. Problems with who had awareness, who needed awareness, the type and degree of awareness required, and the communication of awareness, continued to have an impact on the experiences of at-risk adults and carers. Awareness influenced responses. The middle of the narrative focuses on how at-risk adults and their carers responded in the social context of choking, specifically to the presence of risk. This chapter is divided into three sections: the first introduces the category of response, the second explores the challenges of reducing risk and the final section explores challenges to the desirability of reducing risk. Both sections two and three are densely populated with the happenings and actions that were a part of the middle of choking stories.

SECTION 1: INTRODUCING THE CATEGORY OF RESPONSE

In the social context of choking, how an at-risk adult or carer responded would be influenced by their awareness. ‘Response’ is being defined in this study as *the engagement with a concern*. Awareness was an impetus for response. If awareness was present, not present, or lacking in some way, this impacted on responses in the social context of choking. Those involved in the social context of choking can be seen to respond, not respond or partially respond to the concern presented, with multiple consequences.

The beginning of the choking narrative focused particularly on whether the risk of choking was identified by the at-risk adult or their carers. Awareness of risk did not necessarily mean the risk was addressed, but without awareness it was difficult if not impossible to engage with the concern of risk. The middle of the choking story therefore focuses on when risk was known or suspected

and how the at-risk adult or those caring for them engaged with concerns connected to it; in essence how did they manage risk. The middle of the narrative showcases responses related to the prevention of risk and those focused on other considerations such as quality of life.

There is an underlying premise in this study, by virtue of the nature of the data explored, that responses of interest from a coronial and clinical view would be linked to addressing choking risks. Expectations of response in coronial reports were rooted in a prevention philosophy. Responses in the social context of choking were therefore as a starting point compared and contrasted with what might be expected. This analysis highlighted why expectations of prevention (and in the end of the narrative interventions in response to an actual choking event) might not be met, the consequences of meeting or not meeting such expectations, and the identification of different expectations that may need acknowledgement in the social context of choking. It was the teasing out of 'met', 'unmet' and 'different' expectations in the middle of the choking narrative that illuminated the different dimensions at play in the category of response.

Contrasting 'responding', 'not responding', or 'partially responding' to circumstances in the social context of choking illuminated multiple dimensions of the concept of response. These dimensions, in addition to awareness, included: aims of response; quality of response; competing responses; external factors affecting response; and impacts of response.

Preamble to Sections 2 and 3

Geoffrey, whom we met in the beginning of the choking narrative in Chapter 5, knew he had swallowing problems; he routinely modified his food, choosing soft fish over meat, and spitting food out when he felt he could not swallow it safely. Geoffrey was at a social event when he altered the texture of his food to a more challenging option. He was at a restaurant with his daughter and a friend when he: *"...ordered a scotch fillet steak which surprised his daughter and friend [who knew of his swallowing problems]...*

after attempting to swallow the steak [second mouthful] Geoffrey began to experience difficulty” (068 Police report). Geoffrey made what appeared to be a spontaneous choice, possibly influenced by context (being at a restaurant) and the presence of ‘treat’ food. He chose to forego his normal caution. In that moment his aim in regard to eating appeared to shift from one of safety to one of pleasure and he responded to this change in goal by ordering a steak. Geoffrey fatally choked on the steak. Geoffrey’s story illustrates that prevention and safety – which tend to define the management of choking in the clinical context – may not immutably define or determine action in the social context of choking. The middle of the choking narrative explores the challenges of risk reduction, including whether it is always desirable in the social context.

SECTION 2: CHALLENGES TO REDUCING RISK

Maggie’s story initially provides an insight into a clinical response to choking risk.

Maggie

Maggie, aged 59, lived with an intellectual disability. She lived in a group home with three others and care staff. Maggie’s swallowing and eating difficulties were known to her carers; they had been identified and assessed, and she had ongoing monitoring: *“Maggie was placed on a strict mealtime management plan due to her high risk of choking...Speech Pathology reviews over the years noted ongoing episodes of coughing and choking at mealtimes”*. There was a formal, documented management plan in place so that those who assisted her with meals knew how to respond to her difficulties: *“Mealtime management plans were introduced to monitor Maggie’s eating and swallowing issues...”* Specific instructions were provided on how her food should be texture-modified for comfort and safety. Based on the description below, Maggie was on the clinical ‘Texture A’ soft diet, with the extra precaution of meat being minced: *“She was allowed soft food only, which was to be cut into bite size only (no larger than 1.5cm). Her meat dishes were minced and sauce or gravy was to be added to her food to help*

with swallowing". Maggie was to be supervised when eating: *"She was to be monitored at all times whilst eating"*, and required others to give her verbal prompts to manage risk behaviours such as eating too quickly: *"[she] was encouraged to chew slowly"*. As part of her management plan, distractions were identified as needing to be reduced to help Maggie focus on swallowing: *"[Maggie was] not to engage in conversation or move around [while eating]" (250 Police report).*

Maggie's story outlines a common preventative response to choking risk when it has been identified by a speech pathologist. Maggie's difficulties had been recognised, an assessment performed, and a comprehensive management plan formulated that identified specific risk factors and strategies to mitigate them. The clinical goal for Maggie's swallowing problems and eating options was to reduce choking risk. There were prescribed actions designed to achieve this. Maggie had difficulty with self-awareness: *"...not swallowing food properly, regurgitating food and placing more food into an already full mouth"* (250 Police report), therefore there was an expectation that her formal carers would follow the recommendations (because Maggie could not) to achieve the goal. The recommendations needed to be applied in every situation.

Maggie was eating a chicken roll – food that did not meet her management plan – when she choked to death. Maggie *"...was at a special social function at her work placement [sheltered workshop]..."* It was Melbourne Cup Day; others were having the traditional celebratory food associated with that social and cultural event, and *"...Maggie was sat down eating a chicken treat roll"* (250 Police report). The presence of potentially highly desirable food, and the sense of belonging that comes from engaging in cultural events and sharing in such food, may have influenced Maggie's desire to have a chicken roll that day³⁹, or she may have been given it. Maggie had *"...ongoing episodes of coughing and choking at mealtimes..."* There was no suggestion in the police

³⁹ An association between cultural events, special food and choking has been noted in Japan, with choking fatalities higher at New Year when Japanese people traditionally consume Mochi – a glutinous rice cake (Japanese Food Safety Commission, 2010).

report that staff did not know that she needed texture-modified food (TMF) or supervision; the description that she was eating a chicken ‘treat’ roll implies that it may have been just that – a special treat. A staff member was in the area and when Maggie urinated while eating the chicken roll he left to get cleaning equipment and on returning found her slumped forward and unresponsive. Those overseeing Maggie’s care had not responded as expected based on her care plan.

Geoffrey’s and Maggie’s stories suggest that even when awareness of risk exists, sundry other things (such as pleasure choices, special events and competing care duties) might challenge a prevention goal.

Strategies to reduce risk and their challenges

The failure to identify problems or assess their causes in some at-risk adults in the beginning of the choking narrative indicated that the need for protective strategies was not recognised and/or put in place. For others however, assessment and management plans did identify risk factors and strategies to reduce them. The multi-factorial nature of choking required a multi-strategy approach to address its risks, which was noted across individual stories. These strategies included: the texture modification of food; positioning the person in an upright posture; supervision; assisted feeding; verbal cueing; reducing distractions; removal of risk items (food and non-food); and regular review. Food and fluid texture modification seemed a dominant strategy, but it was not the only tactic to reduce risk and possibly not the most salient one. The implementation of preventative strategies went awry in many choking stories and illustrated how complex reducing risk can be when a strategy moves from a recommendation on paper to day-to-day life. Three strategies to manage risk were particularly highlighted in the middle of the choking narrative: assisted feeding, supervision and texture-modified food.

Difficulties with assisting someone to eat

Clara and Janice

Clara recovering from a stroke, and Janice with dementia whom we met in Chapter 5, both required assistance with feeding. As they were both living in assisted-care settings, this was provided by formal carers (nurses in both cases). The assistance they received immediately prior to their choking-related deaths prompted their respective coroners to recommend:

“I recommend that the hospital, by whatever means are considered appropriate, clarify the duties and responsibilities of nursing staff in relation to the actual feeding of dysphagic patients” (136 Inquest).

“A skills assessment of a prospective staff member’s assistive feeding technique should be made prior to employment and regular competency testing carried out during the period of employment as a guide to appropriate training” (088 Finding).

Several dimensions related to the key category of response were evident in these coroners’ comments. The coroners had an expectation that formal carers (here nurses) should have a certain level of awareness and be able to apply that in their responses to the care situation. Other dimensions were also highlighted, including expectations that certain skills were connected to particular care roles, the responses required needed to be communicated, and the quality of responses needed to be assessed and supplemented to meet expectations.

Monica

Assisted feeding often requires the person assisting to have both practical skills and knowledge. Practical skills can include positioning the at-risk adult correctly for eating and drinking, and determining the correct amount of food placed on the eating utensil and its speed of delivery to the mouth, depending on the person’s problems and needs. The choking narratives

showed that the person assisting needed specific knowledge of the at-risk adult's behaviours: *"...the deceased [Monica, 34, and with Down syndrome] is thought to have taken one sandwich and placed it in her mouth whole and has then pushed another sandwich into her mouth on top of it. Apparently this type of behaviour was normal for the deceased"* (181 Police report).

Kevin

Those assisting someone to eat needed awareness of the at-risk person's limitations. One such limitation demonstrated in multiple cases was the at-risk adult's inability or unwillingness to follow instructions, particularly when cognition was compromised. Kevin, 70 years old, had an intellectual disability: *"On numerous previous occasions he was observed to have begun choking on foods because of his eating habits. He had been told on numerous occasions not to eat so quickly. However due to his mental capacity he never followed this"* (039 Police report). Those assisting at-risk adults to eat and drink needed to understand that those in their care may not be capable of comprehending an instruction or self-monitoring or inhibiting behaviours such as fast eating or food gorging. This highlights a dimension of the key category of response: the relationship between the at-risk adult's response to a situation and the carer's response. Delia's choking story tells not only of her failure to follow an instruction but the complexity of Carol her carer's task in addressing the many elements that comprise skilled feeding in the social context of choking.

Delia and Carol

"...Delia and Mrs Robertson were eating lunch. The hairdresser Carol was feeding Mrs Robertson her vitamised lunch and all three ladies were talking. When Mrs Robertson finished her meal Delia gestured to Carol to feed her as well" (002 Finding). Delia, 84, suffered from dementia: *"...Carol asked Delia if she had any food in her mouth and checking after Delia responded negatively."* Here the hairdresser appeared to have knowledge of assisted feeding skills and confirmed the accuracy of Delia's response with physical checking. *"Carol then put some food [vitamised] on a spoon for Delia and told*

her not to eat any bread with it". Carol judged the appropriate amount of food Delia needed on a spoon for safety and gave Delia independence to self-feed. Bread was present; possibly because Delia was eating with other residents who were able to have bread. Delia either did not understand Carol's instruction or wished to have the bread that was apparently in reach: *"Carol sat back down and when she looked over at Delia she noticed that she was having trouble breathing"*. It appeared from the police report and coroner's finding that Carol was tending to a resident's hair while also assisting other residents to eat. Carers multitasking at mealtimes was not uncommon across cases. Carol, seeing Delia in difficulties, *"...immediately got a nurse to come and help"* (002 Finding).

Delia's story illustrates the complexity of the 'simple' task of feeding an at-risk adult. Carol, in providing such assistance, had to apply multifaceted knowledge and skills. She was simultaneously responding to Delia's request for food, checking that she was not at risk from the last mouthful, respecting the partnership nature of feeding by asking for Delia's self-assessment, physically checking the accuracy of Delia's self-report, encouraging independence by assisting Delia physically to self-feed, applying visual checks, applying knowledge of risk by identifying that breathing difficulty was a particular concern when coupled with eating or drinking, responding to that concern by following an organisational procedure, and finally reducing the risk of harm by seeking more expert assistance – all carried out while performing her primary job of hairdressing and assisting other residents to have their lunch. This long list is not exhaustive. It does however, reflect the multiple elements that carers may have to juggle in food-related interactions with at-risk adults, indeed often while attending to other issues. It also demonstrates how integral carer awareness and responses are to the middle of the story for most at-risk adults.

Janice's (088) coroner's call for competency in the skills required to effectively feed someone acknowledged the complexity of feeding assistance and the need to support carer skills. Clara's coroner was forced to point out that such skills may be of no use if there was no one present to apply them:

“...Clara had unilateral paralysis and the protocol called for food to be placed in the unaffected side of her mouth. It is difficult to see how that requirement could be met without the presence of some person to assist her in that regard” (136 Inquest).

Coroners expected that formal carers should respond in certain ways to address risk. Similarly to the key category of awareness addressed in Chapter 5, some carers failed to respond or only partially responded as expected. Considering the awareness and responses Carol had to juggle in assisting Delia, it is sobering to reflect on the expectations placed on formal carers. Perhaps in critiquing care there are assumptions being made that tasks such as assisted feeding are a fairly simple response to risk, when in the social context of choking they may well not be.

Irrespective of the type or degree of response required, any response required them to be present. The presence or absence of others played a significant role in the middle of the story for many at-risk adults.

Difficulties supervising an at-risk adult

Informal ‘supervision’ and the presence of others

Jack and Owen

Regardless of the awareness and responsiveness of carers to identify and manage risk factors for choking, the presence of others to summon help if a choking event occurred, while essential, was not always possible. Some at-risk adults lived alone, or family members and housemates were not present when the choking event occurred. Such was the situation for Jack and Owen. Jack, 53 years old, with muscular dystrophy and a history of choking: *“...lived alone...had trouble when swallowing food...found in a standing position collapsed over the kitchen sink...On the right hand side of the sink was a small packet of chips” (092 Police report).* Owen, 60, had Parkinson’s disease; his wife was out when: *“It appears that deceased was consuming food as he stood in the kitchen and either choked on remnants in mouth [sic]*

or vomited a quantity of food and choked on these food remnants as a result” (165 Police report).

Kevin, Duncan, & Zoe

The communal living of assisted-care settings potentially offered more consistent support than living in a private residence. Other residents who had no familial or professional responsibility to do so, nevertheless on occasion came to the aid of their fellows. Kevin, Duncan, and Zoe respectively were helped by fellow residents when they experienced difficulties: “...one of the residents has entered the kitchen and stated that Kevin was in trouble” [resident alerted care co-ordinator] (039 Police report); “Staff were alerted by other residents that Duncan [90, with no reported history] was having difficulty breathing” (001 Police report); and “Staff at nursing home were alerted by other residents that Zoe [96, with no reported history] was in distress” (166 Police report).

Patsy

The behaviours of some at-risk adults actively thwarted the monitoring and protection made possible by having others close by. Patsy, 47 years old, living with a mental illness and residing in a mental health facility, died in a locked bathroom eating BBQ chicken: “...the deceased had a habit of entering other residents’ rooms and eating their food. The deceased’s former case worker, sister and the caretaker of the lodge all informed police that the deceased would regularly enter other residents’ rooms, steal food and consume the food as rapidly as possible in order not to be caught” (106 Police report). Failure to supervise adequately however, was often due to carer behaviour rather than the at-risk adult’s actions.

Formal supervision

Clara and Michael

Formal supervision by paid carers, even when specifically required and documented in management plans, was not always provided. Clara, with her swallowing and communication problems post-stroke, was left to fend for

herself when the RN helped her commence her meal but then left her presence: *"...certain of the dysphagia protocol requirements...were not adhered to. The deceased had been left alone to feed herself, by the time she was seen again she was in difficulty choking"* (136 Inquest). Michael, 45 years old with a head injury, his family no longer able to care for him, died a fortnight after entering an ACF: *"...deceased would often cough during meals, due to amount of food the deceased would put in his mouth at one time. A recommendation for the deceased to be supervised while eating is noted in his file...It appears no staff were present while the deceased was eating"* (079 Police report).

The failure of staff in assisted-care settings to adequately supervise however, illustrated levels of complexity in supervision that were not always acknowledged. Part of the challenge was the definition of exactly what 'supervision' meant in practical terms; interpretations of supervision could include: being in the room; being nearby in another room; having direct vision of the person from a close vantage point; being at the same table with them; sitting opposite them watching every mouthful they consumed; or the at-risk adult having a call button to summon help. Another part of the challenge was whether being present in whatever capacity was enough.

Maxina

In Maxina's choking story, carers were specifically employed to provide supervision, requiring a carer to be with Maxina when she was eating, yet this did not prevent one of her risk factors, which was food gorging. As the coroner commented: *"I also accept that there was a seamless transition from one carer to another when Personal care assistant (PCA) 2 relieved PCA 1 so she could have her own lunch break. How the deceased managed to 'gorge' her sandwich so as to bring about choking is not clear. The adequacy of supervision may be questionable however, the gorging of itself was consistent with her eating problem"* (024 Inquest). Maxina had dementia and in her choking story the presence of someone supervising, being present and charged with that specific task, was insufficient to provide what the coroner

described as 'adequate supervision'. This possibly links with the risk-reducing strategy of skilled assisted feeding explored earlier in Delia's (002) story. Carers needed to know what they were looking for and how to appropriately intervene, not just 'watch' the at-risk adult.

The coroner in Maxina's story referred to the skill level of the supervising carers and advocated in general for personal carers, who often have insufficient knowledge to do what is asked of them: *"PCAs [personal care assistant] receive basic training...in the absence of regulation [of PCAs] there lacks, in general terms, an ability to monitor the standard of delivery of care...The presence of Registered Nurses would help to support the residents of these facilities"*. Here the coroner was particularly commenting on 'low care' and 'hostel' facilities, where residents are often more independent, *"and the personal carers who increasingly, are the group of employees providing the majority of care in the aged care setting"* (024 Inquest). As demonstrated in the beginning of the choking narrative, nursing staff may also not have adequate awareness or response skills. Multiple and competing nursing responsibilities may 'blind' them to the priority of being present for at-risk adults and concentrating on their eating and drinking, as was possibly the situation in Clara's (136) story above. Trevor's story however, shows both a lack of supervision and evidence that the nursing staff had insufficient knowledge about choking risk to respond to his difficulties appropriately.

Trevor

Trevor 45, had an intellectual disability and severe mental health issues. He had been identified as having eating and swallowing problems: *"...and could not communicate his symptoms, feelings, emotions and thoughts effectively"*. On the morning of his death he suffered a fall, hitting his head; no close observations were made after this event. There was no apparent texture modification of his food, despite Trevor having known swallowing problems. On the afternoon of his fall: *"RN...took dinner to deceased [in Trevor's room]...The dinner consisted of chicken nuggets and chips...RN put the plate*

down next to Trevor on the floor because he was lying on his mattress which was on the floor [RN left the room]. RN said that some time later one of the nurses called out that deceased did not look well...called out that she thought deceased had suffered a cardiac arrest” (138 Inquest).

Unsupervised, with swallowing problems, a possible head injury and likely poor posture for eating – due to his being on the floor – Trevor had choked. The coroner concluded: *“Had close observations been maintained on the deceased, the fatal choking episode which took place in the late afternoon may quite likely have been avoided” (138 Inquest).* Trevor’s identified swallowing problem had apparently not been assessed by a speech pathologist; there was no apparent management plan or care goal to direct how to respond appropriately to his difficulties, such as cutting up his food or texture modification. Basic management skills such as optimal positioning for eating and drinking did not appear to be encouraged or supported by nursing staff. Trevor had a history of multiple hospital admissions for pneumonia, which may have been further evidence of his aspirating food or drink due to his dysphagia.

The absence of supervision makes the successful management of dysphagia and choking risks unlikely in at-risk adults with cognitive problems, and additionally delays help if choking occurs. Supervision however, does not itself guarantee that the at-risk adult would not experience difficulties. The *“seamless transition”* of supervising carers in Maxina’s choking story and yet her ability to *“gorge her sandwich” (024 Inquest)* with this supervision in place, highlighted another complexity of supervision and its relationship to management, namely the speed with which at-risk adults can experience what can be life-threatening difficulties associated with eating.

Gemma & Frank and Leila & Noelle

Gemma and Leila discovered just how quickly events can move from normal to critical. Gemma was on duty at the care facility where she worked, supporting Frank, who was 47 and living with intellectual disability. She had prepared Frank’s lunch and given it to him and then: *“...left the room for*

approximately two minutes whilst Frank was eating and during this time Frank has attempted to swallow a banana too quickly and has subsequently choked...Gemma returned to the room to find Frank sitting in an upright position struggling to breathe and coughing” (188 Police report).

Leila (a home carer) was on a shopping trip with Noelle who lived with a severe head injury. While shopping Noelle, 31 with a brain injury, “...took exception to one of the objects [gained on the shopping trip] and would not relinquish it...Noelle maintained possession of the object throughout the remainder of the excursion. And return trip home” (215 Finding). Noelle still had the object in her possession when they got home. Leila made Noelle a cup of tea and dispensed her afternoon medication. Leila went into the next room to document the medication she had just administered. Family members were nearby in other rooms in the house and responded when they heard Noelle choking: “*The object could be seen inside the deceased’s mouth, but she had clenched her teeth and they were unable...to remove it...*” As the coroner articulated: “*...in hindsight the deceased could have been better visually supervised whilst in possession of the object [Noelle had a history of inserting a towel in her mouth when stressed]. Notwithstanding, it would have taken her seconds to place the object in her mouth and there is nothing to say the removal of the object would have been any easier or successful” (215 Finding).*

Supervision issues in the middle of the choking narrative posed several questions relevant to care. Could supervision be provided given the at-risk adults’ living arrangements? How physically close did the supervision need to be? How skilled did the person providing supervision need to be? What specific behaviours of at-risk adults might challenge supervision? Like assisted feeding, supervision may seem a simple strategy to apply on a care plan, but as a response in the social context of choking it could be highly complex. Noelle was surrounded by carers, both formal and informal. Everyone was engaged in the activities of life close at hand. Leila had two competing care responsibilities – supervision and documenting Noelle’s medication – both potentially related to the reduction of risk. In hindsight she

might have prioritised supervision, but the object was not a towel and Noelle was not reported to be stressed. In the social context of choking there may be a preferred response (often clear in hindsight), but another dimension of response was whether at a particular moment a particular response was feasible, or did circumstances favour another response or require a choice between competing responses. As the coroner stated, it only took Noelle seconds to get into difficulty.

Difficulties with texture-modified food

One element of care related to choking risk which was shown to be highly complex and challenging in the social context of choking was the use of texture-modified food (TMF). Specific texture-modified diets (TMD) may be recommended by a speech pathologist to reduce risk (aspiration and choking) and increase comfort (some food textures being easier to process in the mouth and swallow). There are three standard TMDs clinically used, each of which dictate size of food particle, moisture of food, and softness. As seen in Chapter Five, very few at-risk adults in this study had been documented as having a speech pathologist assessment. Texture modification of food and drink is a common strategy in dysphagia care, but it can significantly restrict the type and nature of food available in someone's diet.

The use of texture-modified diets and food was present in the middle of the choking narrative, however it was often unclear who had recommended it, what the rationale was for a particular texture being chosen, what form or extent of texture modification was being used, and whether it was appropriate for the individual's needs. It is assumed here that such food was being used to manage a swallowing or eating problem and/or to reduce perceived risk.

Doug

Doug, 80 years old, was meant to have his food vitamised: *"As a result of his stroke, the deceased was forced to eat...food puree [sic] as his throat was affected by the stroke. [On the day he choked]...the deceased had a meal at his hostel which apparently included a sausage. As a result of eating the*

sausage, the deceased began to make gurgling noises and found it hard to breathe” (082 Police report).

There was a general expectation by coroners that care (in assisted-care settings particularly) at least partly included provision of the correct TMD to reduce choking risk. Censure occurred from both coroners and family members when this expectation was not met. The coroner reviewing Clara’s story above highlighted expectations underpinning duty of care in the management of risk in regard to TMDs: *“The [facility] protocol also called for vigilance at the time of the delivery and consumption of a meal served to the dysphagic patient. Nursing staff were meant to ensure that the texture, consistency and type of food and fluid provided were as ordered...The nursing staff were essentially the last line of defence against error. This was not a situation where the deceased received a meal that was merely not to her taste. Her diet was as much a part of her management as anything else, and her level of nursing care should have reflected that fact” (136 Inquest).* In Clara’s case the coroner drew a direct link between the failure to provide the recommended TMD prescribed by a speech pathologist and death: *“The provision of a meal that was not in accordance with her stipulated dietary requirements had a direct association with the deceased’s aspiration of food [choking] and her consequent death” (136 Inquest, coroner’s conclusion).*

Len and Karen

Len was 82, living in an assisted-care setting with a history of schizophrenia and depression; he choked on steak at lunch. Karen, Len’s daughter, made comments to the investigating police officer after his death that reflected her unmet expectations of care at the facility where Len lived and died. Karen *“...the next of kin [NOK] stated that she believes that the nursing home had acted negligently in the caring of deceased. NOK stated that the deceased was to be given only pureed food and he should not have been given solid foods to eat. NOK stated that she believes that the nursing home has contributed to the death of the deceased” (110 Police report).*

Expectations of knowledge, responsibility and accountability existed around care and risk reduction when paid carers were involved. The comments of many coroners reinforced the view that 'good care', with its relationship to duty of care, was connected with actions that reduced risk. This is not surprising given that one of the briefs of coronial investigations is to identify factors contributing to a death and *"...make recommendations, if appropriate, that may help avoid similar deaths"* (049 Inquest). The following coroners' comments reflected the idea that the provision of appropriately TMF to enhance risk reduction was important:

"I recommend that the hospital through whatever means are considered to be appropriate, reinforce the necessity for nursing staff to be vigilant to ensure that dysphagic patients receive meals of the correct consistency" (136 Inquest).

"Given the overall circumstances surrounding the deceased's death, I recommend the Facility review their induction, training and supervision of nursing staff to ensure they are aware of all elements of their food management system, with particular emphasis on the procedures for notifying changes in diet made by the Dietitian [sic] and/or Speech Pathologist, and their heightened responsibilities for dietary intake during night shift" (026 Coroner's comment).

When formal caregivers did not give the at-risk adult TM food considered appropriate, criticism followed. Ensuring risk reducing strategies were implemented appeared part of the responsibilities attributed to the label of formal 'carer' and care organisations. As illustrated, when mistakes were made in regard to TM food and death resulted, this placed the care provided by staff members and care organisations as a whole under scrutiny. Coroners assessed situations differently however when family members were involved, as illustrated in Nora's story.

Nora

Nora was 70 and living in an ACF after suffering a stroke. She had a history of choking on food and fluids and was ordered a vitamised (pureed) diet. Her cousin Hillary, knowing Nora did not like the food provided by the facility, brought her a hamburger and chips, relaying the following to the coronial

investigator: *"The food is vitamised and looks like vomit...I put the food down and started cutting up the burger so that she could eat it in small mouthfuls...while I was cutting up the burger Nora grabbed a handful of chips and I wasn't quick enough to stop her. I could see that she wasn't swallowing the food and I said to her 'spit it out'. I then tried to push her forward on the seat and smack her back but because she is a big lady I did not have the strength to get my hand between the chair and her back. I started to panic and was looking around for a nurse..." (052 Finding).* The coroner concluded that Nora *"...died after choking and aspiration on food not supplied by the aged care facility where she was a resident."* The coroner's specification that the food was not supplied by the ACF may suggest that they were not liable for the actions of family members. The coroner made no comment on Hillary's actions which contributed to her death. Family and their responses did not appear to come with an expectation that they had responsibility to reduce risk.

It is assumed that the facility would have had a duty of care to Nora not to provide unmodified food, but family members did not. A caveat to this apparent absolving of family responsibility with respect to provided food was seen in Luke's story. Luke, was 47 with multiple sclerosis and dementia, living in supported accommodation. He had multiple sclerosis and organic brain disorder and was only given pureed food. Several hours after eating his pureed lunch Luke was found dead, having choked on a piece of fruit. As his food was carefully monitored and the facility kept all food secure, the only explanation was that a visitor unconnected to the resident had brought in food which the deceased had somehow accessed. The presiding coroner followed up with the facility two years later to check that procedures were in place to prevent a reoccurrence. Such procedures included:

"...families are interviewed on admission and told of requirement that food is handed in and the reason why, unit has signage at entry and exits which requests food is handed to staff for storage in secure area, kitchen locked unless staff are physically in the kitchen preparing food...these measures were put in place and reflect the heightened awareness and vigilance which is

prevalent in the area of special care units across the organisation regarding the potential danger of food stuffs and other items to residents” (172 Organisation’s review presented as part of coroner’s finding).

A facility therefore may not be considered responsible if unbeknownst to them a resident received unmodified food from *their* friends or relatives, however in Luke’s story the facility was held accountable by this particular coroner for the future possible acts of someone unrelated to the at-risk adult bringing in unmodified food and thereby creating an unsafe environment.

In light of the accountability Luke’s facility was held to, Nora’s story held additional interest around who makes decisions about TMF for at-risk adults, and the accountability for and appropriateness of those decisions. One month prior to Nora’s death she had been assessed by a speech pathologist in hospital who had recommended: *“Nora to continue to receive a soft (moist and cut up) diet and mildly thick fluids (level 150) upon discharge to your [the ACF] care”*. There was no indication in the investigation of Nora’s death that her swallowing problems had increased or that she had been reviewed again by a speech pathologist. Post-stroke, barring further brain incidents or illnesses, swallowing would most likely stabilise or improve (National Foundation of Swallowing Disorders, 2017). Yet someone in the nursing home where she resided had changed Nora’s diet to a vitamised diet that she apparently disliked and which had not previously been considered necessary by a professional who specialised in swallowing. Nora was given a diet she did not like, which prompted Hillary to respond by providing food that Nora fatally choked on. Viewed from a social context, many responses can be made on the behalf of at-risk adults which together or individually may contribute to death.

Controlling risk in assisted-care settings seemed particularly challenging due to the number of people involved, which increased the number of responses required to fulfil tasks such as giving the correct food to the correct at-risk adult. Generic infrastructure and knowledge problems were present in many stories. The robustness of assessment and documentation was questioned in

multiple cases: *“Assessment: The level of the patient’s assessment [considered inadequate on review] increased the likelihood that key patient care and risk factors failed to be identified and considered for implementation of the multidisciplinary team” (223 Finding)*, while in another finding, shortcomings included: *“...amendments to documentation, assessments, dietary profiles and care planning...issues including missed opportunities to identify prior choking episodes, shortcomings in documentation and information transfer, staff training and ambulance access” (049 Inquest)*. Care plans were also found to be inadequate and poorly reviewed: *“In my opinion deceased’s care plan was inadequate in that it failed to properly set out, with appropriate prominence, his at risk behaviour...” (159 Inquest, coroner’s comment)*.

The responses of some assisted-care settings fell short of expected care. The death of an at-risk adult at times seemed the only trigger which identified procedural issues: *“The Executive Officer of the home gave evidence and acknowledged that it was unacceptable that deceased’s care plan was not reviewed in 6 months” (159 Inquest)*. Inadequate staff orientation and training exacerbated process problems. As in Nancy’s story, staff in other facilities had trouble identifying risky food: *“Opportunities were missed to identify food, such as a sausage roll provided to deceased on the night of her death were not included in her diet” (049 Inquest)*. Infrastructure problems which impacted on the type of response possible varied between facilities; equipment function and location compromised staff action in some cases:

“A portable suction unit was brought to the room with the intention of using it to try and clear deceased’s airways. However the device was inoperable because the oxygen cylinder which powers the unit was empty...The centre’s automatic external defibrillator had been brought to deceased’s room...It reported no shock advised. It also indicated its battery was low [battery had to be changed]” (223 Finding).

Even when equipment was operational, it might not be locatable at the time of need: *“RN asked staff member to go and obtain an oxygen cylinder with a*

suction facility from another unit. Staff member ran to the other Unit to obtain the suction equipment but the staff could not locate it” (061 Internal review).

Coronial recommendations documented specific problems and called for improvements to the infrastructure of organisations and staff orientation and training:

“Shortcomings...standardisation of the procedures across all facilities...supervision of residents through mealtime...amendments to documentation, assessments, dietary profiles and care planning” (049 Inquest).

“Proper and accurate reporting of all resident incidents is also emphasised to staff to enable near misses and trends to be identified and dealt with” (049 Inquest).

“I recommend that the special unit review their induction, training and supervision of nursing staff...” (026 Finding).

As with the key category of awareness, coroners and indeed managers of some healthcare organisations had expectations of what responses should occur. Critical to these expectations was the presence of an underlying goal that everyone knew, and which assisted care settings and formal carers in particular were expected to support by their actions. When responses fell short of or went against the goal, criticism and recommendations to improve responses followed. This goal (either stated or unstated), as illustrated by the stories discussed, was principally one of risk reduction and prevention. It was incumbent on care staff to provide supervision, skilled assistive feeding and TMF to reduce risk of choking and associated death.

The middle of the choking narrative could potentially end here if only the clinical context of choking and the goal of prevention were being considered. In regard to prevention, the middle of the narrative showed deficiencies in the responses of organisations and carers (both formal and informal) to reduce risk and prevent choking. The identification of such deficiencies might lead to increased awareness through knowledge, training and better organisational processes, and thus improve and increase more appropriate responses.

When viewing choking stories from within their social contexts however, two aspects seem particularly important to acknowledge. Many responses by organisations and carers did attempt to support risk reduction, but the responses were not sufficient to protect the person, highlighting that risk reduction and prevention can be so multi-dimensional that control is not feasible. There was the additional suggestion in some stories that there might be goals other than reducing risk. Both of these aspects will be further explored in the next portion of the middle of the choking narrative.

SECTION 3: CHALLENGES TO THE DESIRABILITY OF REDUCING RISK

Lack of awareness and failure to respond appropriately – by at-risk adults, formal and informal carers and organisations – undermined risk reduction and the prevention of choking. This next part of the middle of the narrative challenges the notion of what is an ‘appropriate’ response in the social context of choking.

The following stories challenge the idea that a risk reduction, preventative approach to choking is or should be the sole focus of care. As already discussed, TMF is one of the key strategies in managing choking risk. However, as noted in Chapter 2, in addition to its physiological impacts and clinical utility, food and its form can have significant social, cultural, spiritual and psychological meanings for people (McInerney, 1992) and therefore the significance of normal food versus TMF may transcend the consideration of choking risk.

For some at-risk adults, even if they would prefer not, changing the texture of their food may make it more comfortable to swallow and reassure them that they are reducing their risk of choking and other risks of dysphagia. However as illustrated in the following stories, TMF may be considered by other at-risk adults as unacceptable. In the social context of choking, food and its form can become a point of tension, resulting from its possible dual functions as a strategy to reduce risk and as a life enhancer; functions that for some at-risk

adults are mutually exclusive. TMF is not the only strategy that can create tension in this social context. Supervision versus privacy and being fed by someone versus independence are other dynamics that can challenge the goal of risk reduction. While present in this study and illustrative of the complexity of prevention and risk strategies with respect to choking, these last two dynamics were not as frequently encountered as were the tensions between TMF and normal consistency food.

In further exploring the challenges around food in the social context of choking, it is worth noting three social variables identified in the middle of the choking narrative which may be present for at-risk adults: they may or may not have decisional capacity; they may be dependent on someone feeding them because of physical disability; and/or they may, because of living environment or physical disability, only be able to access food through the action of others. These variables potentially mean others have control over what and how they eat.

Preferences beyond the reduction of risk

Lara and Richard's stories illustrate that some people do not see TMF as a positive in their lives:

Lara

Lara, in her 60s, had mental health problems and a life-limiting illness. She was living in an ACF. She also: *"...had a history of difficulty swallowing. It was recommended that she be given a vitamised diet; however she did not like that type of food and declined to eat it. Instead she was given a finely chopped soft diet"* (254 Finding). Lara's preference was acknowledged and acted on. Unfortunately on the day of her death she tried to eat a large piece of meat, deviating from the finely chopped diet and choked.

Richard

Richard was over 80 and resident in an ACF, with a history of strokes, dementia, mental illness and an eating disorder. Richard *"...fills mouth with*

large amounts of food until he can't fit anymore in. This was remedied...prior to his death when he came to the aged care facility and was only fed pureed food..." At some point this 'only' was altered to: *"...However normally at lunch time he is allowed to have a normal meal"* (084 police report). Richard fatally choked on fish and chips; his favourite meal and which he had previously choked on. The previous time he choked on fish and chips he was on an outing with his wife; the second, fatal time he was on an outing with fellow residents and a staff member.

In neither of these situations was there coronial criticism of care. Lara and Richard both had preferences that were not supportive of risk reduction. Both scenarios suggest however that they had preferences that were supported at least partially by those around them. In Lara's case there was a compromise on the level of texture modification, with the possible goal of balancing her preferences with potential risk. Richard was able to have his favourite food once a week. In the middle of the choking narrative, preferences that might seem to support quality of life considerations beyond that of safety emerged. What was also evident was that the texture of food was unlikely to be the sole factor in either causing choking or choking fatality.

Choices to forego the potentially risk-reducing properties of TMF were made in both assisted-care and private accommodation settings.

Judith and Christopher

Judith was 57 and had a long-standing neurodegenerative disease and lived at home with her husband Christopher. She had *"...cognitive impairment and recurrent depression..."* and was *"...unable to feed herself and had difficulty swallowing food."* It was noted in the coronial investigation that a pureed diet had been recommended⁴⁰. Judith *"...did not like to eat her food pureed, often resulting in episodes of choking."* She *"...was totally dependent on carers..."* as she was unable to access food and required others to feed her. Physically dependent, Judith was fully reliant on the practical support of others, in

⁴⁰ A pureed diet represents the greatest degree of texture modification and therefore is the most highly restrictive as some foods cannot be pureed. It is also potentially the least acceptable and palatable as perceptually it is the least like a 'normal' diet (Swan et al., 2015)

particular her husband. This reliance meant her choices of whether to reduce risk by eating TM food or to forego such food for pleasure or otherwise had to not only be physically but potentially philosophically supported by others.

If someone – with or without awareness of risk – refuses to eat TM food, a potential quandary for both formal and informal carers arises. Forcing someone to eat TM food when they do not like it may lead both to an increased risk of malnutrition through disinterest in food or – paradoxically – increased choking risk if the person physically resists chewing or swallowing it. Quality of life considerations such as enjoying food may be considered important – to both the at-risk adult and their formal and informal carers; important enough to trump some risk-reducing strategies.

Christopher appeared supportive of Judith's preferences; providing and feeding her normal-textured food even though it caused choking. On the day she died, Judith was: *"...at home having a meal of sausage and bread, being assisted by her husband...The deceased took one bite and started to choke. She took a deep breath and took another bite."* The description in the investigative report seems to indicate that Judith may have lacked awareness around choking events as she did not appear to pause and recover when she started to choke, rather, 'taking another bite'. This may have been a sensory lack of awareness and/or a cognitive one. When Judith did choke, Christopher was prepared, applying first aid: *"The deceased coughed and regurgitated some of the food. Her Husband delivered her several blows to the back."* In practically supporting Judith's choice, Christopher had to deal with the consequences. The coroner's conclusion was: *"...on information available I am satisfied the deceased suffered from a neurodegenerative disease and was unable to swallow food properly. While being fed a meal she choked on a piece of food causing death. I find death arose by way of accident"* (253 Finding).

The middle of Judith's story illustrated that when problems were identified (problems that would increase in severity due to her progressive illness) there were a number of possible responses she and her husband could

make, specifically: reducing risk (following a pureed diet); supporting preferences (refusing to follow a pureed diet); or potentially having some pureed food and some normal-textured food. A decision was required. We do not know if Judith had decisional capacity at the time, or if Christopher's decision to comply with her rejection of pureed food was based on knowing what she wanted, or projecting what he thought she would want, or responding to her in-the-moment wish. What is clear however, is that both Judith's and Christopher's responses involved risk. Judith's risk was that she might die, and Christopher's that he might have to watch his wife choke and die. In the social context of choking, choices and responses to those choices potentially impact on everyone.

A complex and confusing part of the middle of the choking story begins to emerge between juggling strategies designed to reduce risk, with enabling choices, upholding duty of care, and promoting quality of life considerations. The confusion lies partially in the evidence that while coroners supported risk reduction and criticised care when it was not present, there were circumstances where they accepted lack of risk reduction without criticism. It is important to understand what these circumstances might be for all involved.

The complex dilemma of risk reduction versus supporting preferences beyond risk and the possible approaches to this are strikingly illustrated in Harold's (227) and Willomena's (093) stories. The middle of Harold's choking story involved a 'magic door' which on the one side supported a duty of care by carers to reduce risk and on the other side supported preferences beyond risk. Harold, 43, lived in a group home. He had a significant mental illness and an intellectual disability, but in regard to the latter diagnosis was considered to be 'high functioning'; he did however require support in decision making.

Harold

Harold's swallowing problems and risk of choking had been identified and a TMD recommended, which the staff at the group home adhered to: *"As a result of the mouth and throat issues [not specified in report], whenever eating Harold required his meals to be cut up into manageable bite size pieces, particularly steak, sausages and chicken, as he was at risk of choking"*. Strategies had been put in place in addition to the TMD to reduce risk and included supervision and verbal instructions. Multiple risk factors had been identified for Harold and they were being addressed by care staff in his assisted-care residence: *"Staff at the premises were advised to remind the deceased to slow down whilst eating..."* Harold did not have full decisional capacity and required support in decision making which it appeared he was receiving: *"Harold was cared for under the guide of an individual personal plan that was developed between Disability service and the Public Advocate...to address his day to day activities, health and well-being..."* Harold's story has some resonance with that of Geoffrey (068) whom we encountered at the opening of this chapter and earlier in Chapter 5, in that both gentleman were physically independent and visited eating establishments as part of their social activities: *"...Harold was seen as quite an independent person...who would travel to the shops alone or with friends...was able to make choices in regard to social engagements and social interests..."* Indeed, Harold was *"...under no order to remain at the premises"* (227 Finding).

It is unknown whether Harold chose food of a particular texture to offset his difficulties when he was outside the group home. Unaccompanied by a carer, Harold had sole responsibility for his food choices when out. Staff however were expected to fulfil risk-reducing actions in relation to food consumed by Harold in the facility. Harold's story illustrates the interesting line that was drawn by the organisation and the deceased's surrogate decision maker (Public Guardian) in regard to responsibility and care for his eating difficulties. He had self-responsibility outside 'the door' of his assisted-care residence, but this responsibility was assumed by others when he passed

through the door into the assisted-care setting. The imperative of risk reduction by others only existed when Harold was on the premises.

On the day of his death, Harold had been out having a coffee before returning to the group home. Harold died that evening after being supervised when eating supper. He choked in his room sometime after eating. The freedoms he had such as access to unmodified food and unsupervised outings (which were potentially high-risk) did not contribute to his death. Restricting his independence to reduce potential risk situations would have been potentially highly detrimental to his quality life.

Harold's high mental functioning and physical independence gave him partial control over his preferences. The emphasis on and responsibility for risk reduction based on what side of a – literal – door a person is situated is an intriguing one however, and highlights the complexities created when multiple people are involved and expectations exist about what constitutes care. The risk created by Harold's dysphagia and eating behaviour was present both in public and in the facility. His carers were only held accountable however to monitor and respond to risk when he was on 'their' side of the door.

Harold's story seems to show attempts to juggle perceived obligations to reduce risk as part of duty of care in assisted care settings alongside of QoL considerations. Harold, by virtue of his independence and the acceptance of this by others, was able to make choices. In contrast, Judith was totally dependent; however if circumstances had been different and her husband had not been able to care for her at home, living in an assisted-care setting would likely have radically altered her choice in regard to what she ate. Responses in both Harold's and Judith's stories were linked to control; control which was socially connected to the living environment and how the goal of care was perceived.

Willomena's story explores further responses connected to control and highlights the dimension of having boundaries to responses. Her story illuminates limits applied to risk reduction, QoL considerations, and control responses.

Willomena

Willomena's story (093) is one of trying to balance the dual imperatives of risk reduction and QoL considerations. Compromises to risk-reduction-based-care did play a part in Willomena's death, but it is a story that speaks to the notion of risk reduction – at what cost? Willomena choked on a bun: *“Although a risk of choking was identified Willomena was permitted to consume items purchased at the kiosk which she took to the ward where she obviously consumed it [the bun] with haste”*. Willomena's story was particularly complex, pairing a lack of decisional capacity with physical independence and residence in a mental health facility. Willomena, 40, had lived in the facility for many years due to severe mental illness and intellectual disability. Her eating problems, particularly her speed of eating and choking risk, had been identified: *“The seven volumes of hospital files relating to the deceased record an extensive history of monitoring of the deceased while at hospital...”* There were regular review meetings with the care team and senior staff, to explore how to manage Willomena's entrenched and risky behaviours around food: *“...issues relating to her dietary control were usually discussed at team meetings each month”*. Risk management strategies were in place, including her being *“...supervised at meal times when she often attempted to steal food from other patients”*. Her problems however were exceedingly complex and problematic, given that she had: *“...psychotic symptoms which included excessive intake of water...Willomena's polydipsic [excessive water consumption] behaviour became one of the major problems in her management and electronic toilet doors had to be installed to restrict her access to water from the tap and water bowl”*.

Willomena's psychiatric and cognitive difficulties, coupled with her normal physical abilities, made providing care very challenging, which was acknowledged by the coroner: *“Unfortunately she was an extremely difficult patient to monitor”*. Willomena's story demonstrates the importance of food in a highly restricted life. Willomena had been identified as a choking risk but was permitted to consume items purchased from a kiosk. While her access to

purchasing unmodified food could have been prevented, the coroner recognised and conceded that tolerance of some risk was permissible in order for her to have some QoL: *“The deceased was always at risk of harming herself because of her mental condition but was provided some limited freedom”*.

“While it could be said that the deceased might have been supervised more closely at the time when she consumed the bun, there was always the potential that she would be able to consume food with undue haste”. Here the coroner acknowledged that the choking risk of fast eating coupled with physical independence (self-feeding and the ability to move or turn away from others) could lead to difficulties so quickly that even with supervisors present it might not be controllable. In Willomena’s choking story Elliot, her supervising carer, was briefly distracted by another resident’s needs. While strict supervision is protective, a physically able person can intentionally or unintentionally act to undermine it: *“The deceased could not have been prevented from ever having unsupervised access to food except by taking an extremely intrusive and restrictive approach to her supervision”*. In this case the burdens and benefits of risk control had been evaluated and it was considered in Willomena’s best interest to allow for some freedoms to enhance her QoL. She was therefore allowed to partake in chosen social events and purchase food from the facility kiosk.

“These freedoms were clearly intended to provide the deceased with some quality of life in her otherwise very controlled environment”. The decision of best interest appeared in this case to have been made by the facility and its staff. The decisions that allowed for ‘limited freedoms’ appeared to have been extensively discussed and considered, and there were extensive supervisory strategies in place to reduce risk and minimise harm. Advocacy for both risk reduction and QoL was apparent. Responses for risk reduction and QoL co-existed.

As the coroner concluded: *“In my view the files demonstrate very considerable monitoring and supervision of the deceased over many years*

and it was not unreasonable to provide her with a certain amount of privacy and some limited freedoms...In these circumstances her tragic death following a most unfortunate life was not unexpected. In my view the quality of supervision and care of the deceased at Hospital was generally good” (093 Inquest, coroner’s summary).

There are a number of salient points in the final sentences of the coroner’s summary. At the core of this quote is a consideration of what is and is not reasonable risk and what is and is not reasonable control; illuminating that degree may be a significant dimension of response. Multiple risks were identified, including those generated by QoL concerns. In the inquest documentation there were repeated comments on the number of risks present for Willomena and the extensive attempts made over many years to control these. Risk control was a primary focus of care, however it was acknowledged that this control potentially severely limited QoL opportunities. It was not seen as unreasonable to tolerate some risk for the purpose of providing some QoL, even if such tolerance might contribute to death, which in this case it ultimately did. Willomena’s story illuminates that an aim of controlling for all risk to prevent death might be both inappropriate and impossible, and not in the at-risk adult’s best interest. It also identifies that an at-risk adult’s lack of decisional capacity may not preclude them having some of their preferences respected.

There was an additional element of note in Willomena’s story which could have significance for the management of choking in relation to both food preferences, TMDs and the needs of others. Willomena had “...very poor impulse control...[and]...experienced hyper-arousal which lead to unprovoked assaults on other patients and staff.” Restricting preferred food or attempting to remove food in the context of her mental difficulties and physical abilities could have led to her striking out and putting other residents and staff at risk. This case and similarly complex ones show a matrix of inter-relationships where concern (whether related to risk or QoL) cannot just be limited to the at-risk adult. There had to be awareness of the needs of others in the social context of choking who might also be at risk, albeit for different reasons.

For the at-risk adult and their lay and professional carers, navigating the potential conflict between reducing risk (to preserve life) and promoting preferences and choices (to make life worth living) is extremely challenging. This is particularly so when the at-risk adult is in assisted-care settings and the organisation and staff may be committed to or feel they must promote a prevention approach.

Balancing risk reduction and promoting choice considerations

Comparing the middle of Ian's (218) and Ruth's (223) stories provides some guidance on what elements may be important to the successful navigation of promoting preference and choice and risk reduction considerations for all concerned. In doing so, based on coronial evaluation, they provide insight into the dilemmas attendant on responses that go beyond risk in the choking narrative; namely, who should be making decisions, an expanded view of duty of care, and associated ramifications. These stories clarify that the decision between reducing risk and supporting preferences may not be as important to determining good care as having an appropriate, well executed decision making process that defines possible responses. Such a process would enable at-risk adults to make choices (that may reflect their QoL preferences and involve risk) but not hold carers and organisations responsible for not reducing these risks.

Ian's and Ruth's stories: Navigating risk and beyond-risk choices

Ian's and Ruth's stories had characteristics in common; they had decisional capacity, were living in assisted care settings, and were alone and eating their preferred texture of food when they choked. At the time of their deaths, Ian and Ruth had both rejected TMF based on QoL considerations, and were supported by staff in their decisions. The coronial assessments of Ian's and Ruth's care were however very different. In Ian's case, the presiding coroner concluded: *"It is clear on the evidence before me, the deceased received impeccable care and support whilst living at the nursing home, from both the staff of the home and from his loving wife"* (218 Finding, coroner's conclusion).

In contrast, Ruth's coroner concluded: *"Deceased's death was accidental but preventable. It was a direct consequence of the Nurse's decision to permit deceased to eat a meal which contravened her 'soft' diet...I accept that the Nurse may have been motivated by a belief she was enhancing the deceased's quality of life and thereby acting in the best interests of her patient. However her decision was, in my view, an error and should not have been taken..."* (223 Internal Review, coroner's conclusion).

The middle of Ian's and Ruth's stories helps unravel what might constitute the appropriate elements of care when risk reduction and QoL considerations are in conflict.

Ian

Ian, 47, had a neurodegenerative disease but no reported cognitive difficulties. His swallowing problems had been identified: *"...He was at a stage where he had difficulty swallowing..."* He was significantly physically disabled and relied on others to provide his food: *"...but he was still capable of feeding himself and raising and lowering his own bed."* Ian's wife Diane reported that: *"He was a fiercely independent person and would not allow anyone but myself on rare occasions to feed him."* It appeared that assisted feeding provided some benefit, including possible reduction of fatigue, safer positioning, better placement of food and so on, but was largely rejected by Ian. Nursing staff corroborated Diane's evaluation of Ian's character and what was important to him: *"...a fiercely independent person who did not like to socialise with the other residents..."* The facility and staff respected his personality and social preferences by not requiring him to eat in the dining room or only to eat TMF. Ian ate unmodified food alone in his room with no supervision. Ian did not want to follow a TMD, be supervised or fed, all of which would have potentially reduced risk.

In regard to his swallowing problems, all food provided at the facility was partially texture-modified in response to Ian's identified difficulties. Ian *"...would receive all his meals cut up and usually would consist of soft food stuff..."* However, Ian additionally had access to non-modified food which he

ate unsupervised in his room – despite the risks: *“Ilan liked to have lollies in a container at his bedside and he particularly liked fruit as well...”* Ilan was routinely provided non-modified, potentially high risk food by friends and family: *“Anybody who visited Ilan usually took him some snacks... This really helped to keep [his] independence”* (218 Finding, wife’s statement).

Ilan’s access to non-modified food was an acknowledged practice identified as important to his QoL. The practice was not hidden; the supplied food was on display in Ilan’s room and at his request. Safety measures such as supervision or assisted eating to help mitigate the risk of the non-modified food were not in place because of Ilan’s explicit decisions. Ilan did however reside in an assisted care setting, which meant others had a duty of care for him. This duty could have been interpreted solely on the basis of avoiding physical harm, causing conflict between the facility’s interpretation of good care (risk reduction and prevention) and Ilan’s desire for independence. Instead in this case either Ilan’s autonomy was considered the ultimate guide to responses or good care was more broadly interpreted as it was in Willomena’s story; encompassing a balancing of risk with quality of life considerations.

One of the significant elements of Ilan’s story was the partnership between those involved, which was reflected in ongoing communication. Diane commented that she was actively involved in care and kept informed: *“The staff at the nursing home included me in the planning of his care both when he arrived and also during his stay...”* Her input was actively sought: *“... On at least two occasions I helped to fill out a resident care plan to assist in this.”* The degenerative nature of Ilan’s disease was acknowledged and monitored for its impact on his care: *“... I noticed with his illness that it was rapidly deteriorating over the 14 months at the nursing home”* (218 Finding, wife’s statement).

Another notable element of Ilan’s story was that TMF was provided (by the facility) in parallel with normal-textured food (provided by family and friends), so both planned and spontaneous decision making opportunities were

available to Ian. Not only was Ian's decision to have unmodified food respected, but the need of the facility and staff to provide him with the 'safest' diet to support their possible concerns was also respected. Staff and the facility therefore met what could be considered their duty of care to reduce risk by providing the TMD thought to be most appropriate. The result, contrary to usual practice, was not restriction but expanded options. Despite severe physical dependency (paraplegia), Ian had access to a range of choices to both reduce risk and address his preferences. The provision of both TM and unmodified food allowed him to make spontaneous decisions around risk and pleasure depending on his self-assessment at any one time. The 'magic door' of Harold's story was further developed in Ian's, where both risk-reducing and preferred food options were equally available within the facility.

However, it was apparently perceived as important to staff that they not provide Ian with unmodified food (whole fruit and lollies), thus while respecting his choices, their direct actions remained aligned with risk reduction. The facility staff were able to report that Ian's difficulties with eating had been identified and acknowledged, and appropriate, documented management was available: *"The deceased has meals prepared by staff and cut up for him, as he has a great deal of difficulty in eating"*. The staff were able to report on Ian's choices, responses and active engagement in self-care: *"He does not take prepared meals regularly and often eats fruit and lollies in bed..."* It appeared important to the staff/facility in Ian's story to clearly represent their role in his eating: *"...RN stated the items [fruit and lollies] were not given to deceased by staff" (218 police report)*. Staff told of their desire and response in providing the perceived 'safer' (modified) food, and their lack of physical involvement in providing 'risky', unmodified food or feeding it to Ian. This indicated that the dimension of personal or professional values of carers was significant to their response.

If Ian had not died when he did his disease would have likely progressed to the point where he could not access the treats beside his bed, or feed himself, without direct assistance. Whether staff providing or feeding Ian

unmodified food would have been considered negatively by the coroner is unknown. In light of Ian's decisional capacity and family support, refusal by the facility and/or staff to physically accommodate his wishes if necessary may have been considered discriminatory given his physical disability. In the social context of choking, such dilemmas that place the autonomy of the at-risk adult and values of carers or perceptions of duty of care in potential conflict need to be navigated.

What was perhaps the most outstanding characteristic of Ian's story was that QoL considerations were given priority over risk reduction. Risk reduction and harm minimisation were not abandoned, but continued as a focus of care within the boundary set by Ian's choices, however limiting to prevention those choices were. While not supervised, Ian still had access to support, even though events obviously overtook him at the time: *"The deceased had a bedside buzzer to alert nurses of emergencies, this was not activated"* (218 police report). On the afternoon of his death his wife reported: *"He was in good spirits and appeared to be well cared for. During the visit I discussed with him issues relating to his care. I asked if there were any problems and he said 'No I'm spoilt'. I left him some fruit for him to snack on which included some grapes and probably some plums..."* While eating a plum alone in his room, Ian later that day choked and died.

Returning to the coroner's final statement: *"It is clear on the evidence before me, the deceased received impeccable care and support whilst living at the nursing home, from both the staff of the home and from his loving wife"*. In Ian's story, 'impeccable care' included addressing QoL needs even though they hampered the ability to reduce risk. In Ruth's story by contrast, addressing QoL needs did not lead to an assessment of impeccable or even good care by the coroner presiding.

Ruth

Ruth, 74, had a stable swallowing problem of many years' standing after suffering a stroke. In the past, tube feeding had been contemplated but refused by Ruth. The middle of Ruth's choking story was triggered by her

hospitalisation for an unrelated issue. Her swallowing difficulties were reassessed and a TMD was recommended pending her consent: *“Whilst an in-patient she was reviewed by a speech pathologist who recommended [researcher emphasis] that Ruth maintained a diet of thickened fluids and pureed foods... This diet had on previous occasions been recommended to the deceased but she had at times been non-compliant...”* Ruth had had dysphagia for over a decade. In keeping with general speech pathology practice, the recommendation would reflect the safest (prevention of aspiration and/or choking) food/fluid consistency for the individual’s particular swallowing problem. On discharge to another facility to facilitate her recovery from her current medical condition, Ruth’s speech pathologist communicated the following, outlining her providing informed consent: *“Ruth has impaired swallowing reflex and has agreed...to have her fluids thickened and maintain soft diet [researcher emphases]”*. This information was recorded in the care notes in the health facility where Ruth was now residing. She had not agreed to a pureed diet but had compromised and agreed to a soft diet. It was documented that historically she had previously deviated from the recommendation of pureed food, so the soft diet decision appeared to be in keeping with what she considered acceptable long term. Based on her agreement, a soft TMD at this point ceased to be a recommendation and became a prescription to be followed by the care facility she was being transferred to.

There was no suggestion in the coroner’s report that the negotiated TMD in an adult with decisional capacity was inappropriate or breached duty of care. At this point based on Ruth’s documented, autonomous, QoL-based decision, the ‘receiving’ facility’s obligation and the associated duty of care of their staff was to provide the thickened fluids and soft TMD. However, the formal decision processes adhered to in the hospital started to unravel in the new facility.

Approximately a week after transfer to the new facility, Ruth *“...requested chicken nuggets and chips for her evening meal.”* Chicken nuggets and chips are a popular menu choice in ACFs and have been implicated in other deaths

(203). There was no indication that Ruth's decisional capacity or swallowing problems had changed. The request appeared to be a spontaneous, in-the-moment choice⁴¹. Autonomy by its nature includes the possibility that a person's choices and decisions may change. The catering staff, noting that Ruth's request did not match her prescribed diet, questioned the order with the RN responsible for Ruth's care. Processes set up to monitor safety around TMDs in the facility did not fail here; Ruth's request was noted to be contrary to her prescribed, documented TMD, and staff receiving the request queried it with a senior clinical staff member.

The RN *"...directed catering staff to serve the chicken nuggets and chips to deceased on the basis that 'she would try to make them soft'"*. A soft TMD requires the food to not only be soft, but moist, often with a sauce and cut up into pieces 1.5cm x 1.5cm or less (Atherton et al., 2007). When questioned by the coroner, the RN said: *"...that she permitted deceased to have this meal 'in the interests of her quality of life'"* It is likely that Ruth requested the chicken nuggets and chips based on an 'in the moment' desire related to QoL; there was no indication in the finding that Ruth and the RN had discussed this request, which was contrary to Ruth's previous decision (223 *Finding, description of events*).

It is unlikely any discussion about Ruth's choice not to follow her previously agreed TMD took place, as despite her voiced intentions the RN was not present to modify or supervise Ruth's eating. *"It was Ruth's practice to eat her meals alone in her room..."* This may have been a QoL-related choice or because Ruth was not considered to be at high risk when eating the prescribed TMD. Neither the RN who authorised Ruth's request, nor any other nurse was present to try and modify the food or supervise the eating of a more difficult food consistency: *"...Ruth was served her meal... The meal was placed on a trolley in front of her. She was left to feed herself without assistance..."* In the absence of supervision there was a bell present which

⁴¹ Not unlike Geoffrey's choice of ordering steak when out at a restaurant despite reported difficulties with swallowing and need to have soft food (068).

the deceased was able to activate: “...deceased activated her nurse call button and staff promptly attended” (223 Finding).

When comparing Ruth’s and Ian’s choking stories, both individuals were in assisted-care settings, had decisional capacity, made preference-based choices, had those choices respected by the staff caring for them, and choked alone eating their preferred food. But some of the characteristics that were part of defining good care in Ian’s story became distorted in Ruth’s. The coroner in Ruth’s story concluded that her “...death was accidental but preventable. It was a direct consequence of the Nurse’s decision to permit deceased to eat a meal which contravened her ‘soft’ diet and was contrary to her nursing plan”. In the social context of choking, responses to decisions are important to unravel. Confusion about what constitutes a perception of good care creates vulnerability for at-risk adults (threatening QoL based choices), formal carers and facilities (threatening their practice and reputations).

Teasing out Ruth’s coroner’s comments, several issues arise relating to decision making around risk and choice. Ruth’s death was directly linked with the decision and action of a person who was, by their duty of care, responsible for her. It is important to note that Ruth had already decided upon a more high-risk diet through her original, informed refusal of the pureed diet recommended to her. The primary issue subsequently became ‘On whose decision was the action of introducing more risk based?’ It appears that it was the nurse’s opinion of the importance of Ruth’s expressed preference to her QoL that was the main motivating force. This opinion was apparently not clarified with Ruth, who had made a request in regard to a single meal. Investigation of why the request was being made would have been prudent; it may have been prompted by something as simple as disliking the soft menu option for that meal, which was an issue which could have been addressed without increasing risk.

The RN defended her decision to allow the chicken nuggets and chips based on the rationale of QoL. It is questionable whether QoL considerations should be measured to rest solely on the choice of one meal. A soft TMD had been

agreed to by Ruth. Her autonomy would not have been compromised if those responsible for her care (under a formal direction sanctioned by Ruth) had refused the spontaneous request but subsequently reviewed her treatment decision with her. Another issue is the coroner's linking of the death specifically with the changed food texture. The deceased had a history when under her own volition of apparently 'not complying' with the recommended TMD and had not on such occasions 'died' from eating what one assumes to be normal consistency food. This does not absolve the nurse from the decision or actions that followed, but as choking is often multi-factorial, the link may not be as definitive as suggested. The coroner's assessment continued: *"I accept that the Nurse may have been motivated by a belief she was enhancing the deceased's quality of life and thereby acting in the best interests of her patient..."*

A judgment of best interest needs to be based on a detailed understanding of the risks, burdens and benefits of a treatment strategy, as well as QoL and other considerations. The RN's lack of follow up to modify the food and supervise Ruth seems to indicate a lack of awareness of all the factors that should have been considered in an assessment of best interest. The RN appeared to make a decision without fully understanding possible consequences. This view seemed to be embedded in the coroner's comment: *...However her decision was, in my view, an error and should not have been taken, at least without reference to her nurse manager or to the doctor"*. Reference to the nurse manager and doctor here provides for the possibility that a change in the constraints around Ruth's food may have been in her best interests, but not without a more in-depth decision making process. The coroner was not dismissing the importance of QoL, but seemed to be implying that given the risk and possible consequences, an 'in-the-moment decision' of 'allowing' by one staff member acting alone was not appropriate. In summary, the outstanding characteristics of what went awry were: Ruth *and* the nurse both made spontaneous decisions that increased risk; there was no discussion of whether such decisions were in Ruth's best

interest; and there was no attempting a formal process which would have possibly protected both Ruth and the nurse.

The coroner went on to comment on a compounding mistake made by the RN in allowing the requested meal: *“A second error was made by then proceeding to serve the meal...without first putting in place a strategy to counter the increased risk of her choking...”* A common positive characteristic in other preference-related cases was staff acknowledgement of the heightened risk when TMF was rejected by their attempts to mitigate this increased risk. The characteristic in this case of making no practical attempt (despite the RN having voiced that intention) to mitigate risk drew concern and specific comment from the coroner: *“...Such [a] strategy [to mitigate risk] should in the least have required a member of staff to sit with deceased to assist her in eating the meal safely by ensuring that the food was as ‘soft’ as practicable and cut into portions which could be easily ingested”*. This statement from the coroner again does not negate the possible appropriateness of allowing choices that increase risk, but reinforces that when such choices are being enacted, where possible risks should be controlled for. It was Ruth’s practice to eat alone, but unlike Ian’s story there was no indication that she had formally refused the support of having someone present when she was eating. Supervision would have therefore been protective without violating her ‘QoL decision’ and could have been part of judicious negotiation in supporting her request: *“...The strategy should also have insured that the suction unit was at hand and in proper working order”* (223 Finding).

This coroner’s last suggestion about suction indicates his judgement of the importance of doing everything possible to reduce risk and harm within the boundaries of a QoL-prompted decision. The point being made here seems to be that an individual’s decision to refuse one strategy of care (TMF) does not equate to a refusal of all care focused around risk reduction. Ruth wanted chicken nuggets; however she was rejecting TMF, not all care. Whether suction would have been able to extract the obstruction is unknown, but in the social context of choking doing everything that could be done (outside the

constraints of the person's QoL decision) could be important to everyone. Responses supporting risk reduction and QoL considerations were not necessarily mutually exclusive.

Due process

Responding to the concern of QoL had many dimensions in the social context of choking. These dimensions addressed some of the critical issues relevant to the conflict between risk reduction and QoL considerations highlighted in Ruth's story. In analysing the case, Ruth's choice was not argued against nor did the coroner negate the RN's desire to respond to that choice based on a belief that respect for QoL was in the deceased's best interests. What was challenged was the RN's management of the situation; the making of the decision in isolation, against the written instructions in place at the time, and without consultation with more senior staff or Ruth herself. In addition to or perhaps because of this lack of formal decision making procedure, the RN was further held responsible for not putting in place strategies to mitigate the risk of Ruth's choice when she chose to support it.

The possible tension between reducing risk and allowing choice is challenging in the clinical context of choking, where prevention is considered paramount. The social context of choking however identifies that the challenge has to be met. Despite coroners championing death prevention through appropriate reduction of risk, they are neither naïve to the importance of preference- and potentially QoL-based considerations nor censorial when such considerations are included in care, even when that challenges risk reduction. They do however, based on stories like Willomena's (no decisional capacity), Howard's (partial decisional capacity), and Ian's and Ruth's (both with full decisional capacity) seem to support the view that QoL considerations require due process. These processes are reflected in the dimensions identified as being important in responses related to: knowledge and evaluation of burden and benefit of treatment strategies; knowledge of risk factors and how to mitigate them; joint problem solving

(between all parties) and where appropriate negotiated decisions and compromises; communication among all relevant parties; documentation; and finally but perhaps most importantly, reduction of risks that do not compromise the person's choice. These response dimensions would appear to be protective of both the at-risk adult's autonomy as well as of organisations and staff supporting QoL and risk considerations.

While QoL considerations may mean some at-risk adults will reject certain risk reduction strategies such as TMF or supervision, other at-risk adults will have their QoL enhanced by using all strategies to reduce risk. Regardless of what equates to QoL for individuals in the social context of choking, the need to offer risk reduction-based care remains, even though QoL-based decisions may limit the scope of this care. As articulated in Ruth's story, choosing chicken nuggets did not mean a rejection of all care related to reducing risk, nor an absolving of the responsibility of her formal carers to support risk reduction where possible.

The middle of the choking narrative highlighted many of the social phenomena that were a part of the social context of choking. The following stories encapsulate the limitations in being able to control such phenomena.

Circumstances beyond control

Ida's story: Having dinner when 'life' happened.

Ida

Ida, 58 years old, lived with dementia. She had a history of stroke, and resided in a special dementia unit: *"Ida's needs were assessed regularly by the staff. She had been assessed as having a mild cognitive impairment, at risk of falls and as experiencing periods of agitation. She was emotionally labile and cried frequently...Her family were regularly consulted about her care and continued to report that they were satisfied with the care provided..."* Four months prior to her death, Ida had been assessed by a speech pathologist: *"The speech pathologist found that Ida masticated bread well,*

chewing and swallowing appropriately, leaving no residue. However she also found that at times she became distractible and cried. The speech pathologist diagnosed mild to moderate oesophageal dysphagia...[and]...advised that Ida continue on a normal diet but try to discourage distraction (i.e. talking when eating) [and] nectar fluids with all food. The speech pathologist indicated that a review may be appropriate in 3 months" (061 Finding).

Ida's last general care review was eight days prior to her death. There were no reported concerns requiring further speech pathology review. The middle of Ida's story appeared to be clinically 'perfect'; her difficulties had been identified, assessed and were regularly reviewed. Staff usually helped her cut up her food as she had some physical difficulties. She had a care plan that was being followed; she was consuming a normal diet with nectar consistency drinks as recommended. Her family, the overseers of her care, were satisfied that she was being well looked after. But then 'life' happened. Ida was eating her normal diet in the dining room when Bruce, one of the other residents, fell: *"Ida was in close proximity to Bruce...but would have had her back to him. Staff have advised that when Bruce fell, this created a very loud noise. Ida may have received a considerable fright and became distracted from her eating as a result of this. Ida may also have become distracted by the activity created by the staff as they gathered behind her to attend to Bruce."* One of the carers: *"...who was supervising the residents' meals, noticed that Ida was choking."* The speech pathologist's recommendation, which discouraged distraction during meals, did not list another resident falling as a potential risk factor to Ida's eating, nor could it have been reasonably foreseen by those involved in Ida's care.

The unexpected happenings of life can play a significant part in the middle of the choking narrative. Whether these occurrences can be reliably controlled for is questionable. Maggie (250), whom we met earlier, was left alone eating a chicken roll (against her care plan) at a social event. The reason she was left alone was that while eating she urinated and the supervising carer went to get a mop and bucket. Olga (224), was 88, with dementia and a history of

multiple strokes. She had been unwell with gastroenteritis and was reported to be confused the morning of her death: *“About 1300 hrs lunch was delivered to the rooms for those with gastroenteritis...When residents had the illness, they were confined to their rooms for 48hrs...about 1.30pm carer entered deceased's room” [found Olga dead with her meal half eaten] (224 Police report)*. Olga had access to an emergency call button but had not activated it, possibly because of the speed of her collapse, the stress of the moment, or mental confusion.

It is easy in hindsight to say that Maggie's carer should have removed the food before leaving to get the mop, or that Olga should not have been left alone. Cleaning up urine and managing an outbreak of gastroenteritis were responses focused on other care demands and risks and pulled the focus of care away from the choking risks in Maggie's and Olga's stories. Controlling for multiple risks and the unexpected may only be possible with hindsight; the 'in the moment' vagaries of life are inevitable parts of the middle of some of the stories of at-risk adults and their carers. Acknowledgement that life is unpredictable and that foreseeing all possibilities and responding to them is unlikely to ever be possible is an important element of the middle of the choking narrative.

The key categories of awareness and acknowledgement were also present in the middle of the choking narrative. Awareness was intimately connected to whether certain responses were possible. In regard to the key category of acknowledgement which will be discussed in detail in the next chapter, there were four inter-related concerns in the middle of the choking narrative that are noteworthy here. Firstly, when responses by organisations or formal carers failed to reduce the risks of choking, censure did occur from coroners, organisational reviewers and family members. However some at-risk adults, family members, formal carers and organisations supported the notion that quality of life considerations should take precedence over a sole focus on risk reduction and prevention. Additionally, coroners supported such responses that served individual preferential considerations, with the dual caveats of evidence of due process in decision making and the increasing or

maintaining of risk and harm reducing strategies outside of the preference consideration. Finally, choking risk may not always be controllable for multiple complex reasons, including individual decisions, life circumstances and those involved in the social context of choking.

Conclusion

Response was a key category in the middle of the choking narrative. The concept of response related to the engagement with a concern. Two concerns dominated the middle of the choking narrative; a desire to reduce the risk of choking and a desire to acknowledge quality of life considerations as expressed by the preferences of at-risk adults. Favourable (promoting wellbeing) and unfavourable responses were identified in the service of both concerns. The middle of the choking narrative identified that favourable and unfavourable responses were often connected to both level of awareness and competing goals.

As a key category, response had notable dimensions in the social context of choking. Responses were heavily influenced by environment; responses acceptable in one environment were not acceptable in another. Some responses related solely to certain people or roles and when multiple people were involved, the goal and required responses needed to be clear, agreed on and understood by everyone. Expectations of response were often based on a goal or particular aim that someone had; some goals and related actions served at-risk adults, and some served carers or organisations (thus goals and responses can be in tension). Other dimensions of response included that certain actions may require monitoring and be time sensitive and unforeseen circumstances may sabotage expected responses. Finally, responses that contributed to death had different consequences based on who made the response, be that a formal or informal carer or the at-risk adult.

The middle of the choking story is highly complex and multidimensional, and some of the care-challenging elements in this part of the narrative would

follow at-risk adults through to the end of their stories. The end of the choking narrative will continue to reinforce and highlight aspects related to the themes of awareness and response, however it will also showcase more matters that need to be acknowledged and addressed in the social context of choking as the third key category of acknowledgement is highlighted there.

CHAPTER 7: FINDINGS – THE END

Preamble

This is the final in the series of findings chapters and illuminates the end of the choking narrative. Similarly to the middle of the choking narrative, it is a densely populated part of the story elucidating, as it does, many of the happenings and issues around intervening when a choking event occurs. It also highlights the reality that despite the best efforts of those involved, death and associated ramifications may result. This chapter showcases the key category of acknowledgement and will conclude with an articulation of the theory that emerged from this study. The first section will introduce the key category of acknowledgement, followed by a section outlining the challenges and limitations of intervention. The third section will acknowledge end of life in the social context of choking, while the final section will present the theory of considered support which emerged from the data.

SECTION 1: INTRODUCING THE CATEGORY OF ACKNOWLEDGEMENT

The key categories of *awareness* and *response* continued to dominate in the end of the choking narrative. Together they encompass alertness and engagement with a concern or concerns. The third key category of *acknowledgement* is intimately linked with both these, as acknowledgement in this study is conceptualised as *the recognition and acceptance of what concerns were central to the social context of choking*. The key category of acknowledgement emerged in the data when concerns arose that were either not being addressed or only partially addressed. In the beginning of many choking narratives, concerns such as dysphagia or cognitive problems needed to be acknowledged, so that awareness of their ramifications could be established and responded to. In the middle of the narrative, acknowledgement of the importance of the concerns around supervision or the impact of TMF being rejected was critical. These acknowledgements

were often related to choking prevention in the beginning and middle of the narrative and therefore reinforced that focus of care. At the end of the choking narrative however, acknowledgement focused largely on the concern of coping with death.

Acknowledgement as a theme was related to both recognising substantive concerns such as those noted above, and recognising and accepting where limitations and new opportunities for care might lie. Acknowledgement therefore had two aspects: recognising and accepting both what was currently happening and what might need to happen in the future to address the needs of at-risk adults and their carers. The theme of acknowledgement is heavily showcased at the end of the choking narrative, as it is here that broader issues and concerns arose; drawing attention to the limitations of intervention, and in the process leading to a consideration of how care might be expanded to meet needs around end of life in the social context of choking.

The illustrative stories in the end of the choking narrative highlight the theme of acknowledgement; further expanding understanding of what is currently happening around at-risk adults and their carers as they live and die with choking risk. At the conclusion of this chapter the key categories of awareness, response and acknowledgement will be drawn together to elucidate the theory of *considered support* that emerged from this study, which posits what could happen for and around at-risk adults and their carers as they live and die with choking risk in the future.

Introduction to the end

Older adults, with or without medical conditions associated with swallowing difficulties, along with younger adults living with such conditions, potentially have a heightened risk of choking over the normal population; they are 'at risk'. Many at-risk adults however will not experience choking events. This may be due to the absence or mildness of swallowing problems, the use of strategies that effectively reduce their occurrence, or a lack of precipitating

factors. Many of those who do experience choking events will not die from them; their choking stories will be relatively peripheral to their overall personal life stories. There may be a beginning and middle but no significant end to their choking stories. Others however will fatally choke, and the end of their choking story will be documented in coroners' reports.

Aside from the choking individual, those most likely to be part of the end of an at-risk adult's choking story are family members or staff in assisted-care settings; they are the most likely to witness a choking event and potentially watch the person die from it. If not present, they remain likely to find the at-risk adult after an event has occurred, as described in these dispassionate police reports that perhaps belie the emotional experience for family:

"...the father of deceased located her lying unconscious and not breathing on the bathroom floor of the dwelling they shared. The father contacted ambulance and performed CPR until ambulance arrived" (176 Police report).

"The carer son returned...and checked on his mother in her room where he found her lying on her side on the floor, motionless" (184 Police report).

"[Grand-daughter returning home] When she entered the kitchen she observed the deceased on the kitchen floor unconscious" (211 Police report).

Family members may be involved in the end of the choking story in other ways. If the at-risk adult is hospitalised, family may be confronted with decisions about withdrawal of life-prolonging medical interventions. The end of the choking narrative for many is one of unsought and unforeseen exposure to death and its consequences. Recognition and acceptance of this may be an important part of care for at-risk adults and their informal and formal carers.

SECTION 2: ACKNOWLEDGING LIMITATIONS

The beginning and middle of the choking narrative highlighted the challenges of preventing choking; whether risk factors could be recognised and reduced and whether choking events could be prevented. The end of the narrative highlights the challenges of preventing harm once a choking event is underway and explores how death and its consequence arise in the social context of choking.

Evidence from the beginning and middle of the choking narrative indicated that identifying dysphagia and choking risk factors may be problematic for both assisted-care staff and family members. It would therefore seem critical that carers be able to recognise a choking event if identified or unidentified risk factors become expressed as such. As introduced in Chapter 5's preamble to the choking narrative, Jo's (120) distress and panic (reaching for a wooden spoon to dislodge an obstruction) communicated clearly to his family that he was choking. In contrast, Estelle's (094) and Stan's (108) lack of apparent distress deprived onlookers of clues that they might be witnessing an airway obstruction. The ability or inability to identify a choking event, understand its severity and respond to it to reduce harm, were significant elements for at-risk adults and their carers.

Acknowledging an at-risk adult's inability to help

Carers were able to identify a choking event and intervene to try and reduce harm, showing both awareness and an ability to respond. However, carer skills were often not enough; the behaviour of at-risk adults could be self-sabotaging making it extremely difficult for others to provide aid. Despite this, carers tried. Sara's and Nigel's stories illustrate the need to recognise that because of cognitive problems some at-risk adults cannot be partners in care and can indeed make care more difficult.

Sara and Annabel & Nigel and his carers

Sara, 39, with an insatiable appetite due to Prader Willi syndrome⁴², had no ability to control her eating even when choking. Annabel, Sara's carer, had to put her fingers down Sara's throat to remove the meat Sara was obstructing on. This action did not deter Sara, who continued to focus on eating:

"...Annabel has intervened [again] as the deceased has tried to continue eating even though it was obvious that she was still choking" (096 Police report). Nigel, 85 and with a history of stroke and dementia, was *"...feeding himself while being monitored by staff when he was seen having difficulty breathing and was turning blue with his cheeks apparently full of food. Staff attempted to help the deceased empty his mouth but he continued chewing making this task extremely difficult" (203 Finding).* Recognition of the difficulties that medical conditions generate for both at-risk adults and carers when addressing a choking event is important as they may not be correctible or controllable pre or during a choking event, thus acceptance of limitations becomes an important part of the social context of choking.

Mathew and Tania

Mathew and Tania appeared to have some awareness that something was wrong. Mathew, aged 75 and living with Parkinson's disease and depression *"...was eating...[when] halfway through his meal he jumped up from his seat and rushed to the toilet...after a couple of minutes Ava [Mathew's wife] became worried when Mathew did not return and went to find him" (013 Police report).* Tania aged 62 living with a mental illness, had a similar reaction when she began to have difficulties. She *"...began choking and grabbed her throat and walked to the toilet and then collapsed" (065 Police report).* Trying to deal with the problem themselves Mathew and Tania walked away from the help of others.

The presence of others did not mean however that choking was identified or understood, or that appropriate action was taken. Problems with awareness

⁴² Prader Willi syndrome is a genetic disorder of which compulsive eating is primary characteristic (Hurren & Flack, 2016).

and response, present in other parts of the choking narrative, were also evident at the end of the narrative, when substantive awareness and skill based responses to a choking event was critically needed.

Acknowledging the struggles of informal carers to respond

Family members often struggled to identify and respond to choking events. How the at-risk adult responded, the circumstances of people's lives and the capabilities of those present, all impacted on whether aid was possible, with families responding to the extent of their abilities. One of the features of the social context was the different mix of informal carers and what strengths they brought to the challenges they may have had to deal with. When the at-risk adult was of advanced age and living at home, their informal care network may include partners of similar age with disabilities of their own, and/or family members providing care from a distance. Greg and Vera's story and Stella and her parents' story show the complexity of these social dynamics and the impact on choking.

Greg and Vera

Greg (aged 77, with no documented medical history associated with dysphagia) and Vera his wife were at home eating a meal when Greg experienced swallowing difficulties. Vera seemed to have some awareness that Greg was having difficulties but, possibly hampered by her visual impairment, seemed at a loss to identify the nature of the problem or its seriousness: *"Deceased began to choke and wife offered him a glass of water, he did not respond. After a short period wife checked to see if he had a pulse and was unable to locate one. Deceased was still not responding. Wife attempted to locate a pulse approximately 15 minutes later and was still unable to locate one. This time she felt that he seemed to be going cold and called for an ambulance"* (027 Police report).

Stella and her parents

Both Stella's parents were living with neurodegenerative diseases. When Ivan, who was 73 with Parkinson's disease choked, his wife Una did her best, which did not however include calling an ambulance. Stella was unaware that there was a problem until she *"...received a telephone call from another relative, who had telephoned Ivan. The relative advised Stella that her mother answered the telephone and kept repeating that Ivan would not wake up"* (252 Finding). Stella, concerned, went to her parent's house, and found Ivan unconscious.

From a care perspective, and recognising the issues of lack of awareness and knowledge in the above stories, the temptation might be to think providing more education for family members or the putting of systems in place to better manage emergency situations would be appropriate. Indeed these responses might address some issues, but the possibility of choking and the need to respond is only one element of the lives being lived in these stories. Living at home – where risk may be higher and intervention may not be possible – may bring with it so many benefits as to make choking and its management a low priority. Thus acknowledgement is a challenging category; it manifests in the recognition of concerns and understands the dilemma from the dual perspectives of prevention/intervention and whether action to control risk is required or feasible, as well as acknowledging the possibility of acceptance of risk and its consequences.

Acknowledging the struggles of formal carers to respond

Family members and friends struggled to identify choking events and provide appropriate assistance for a variety of reasons, as did formal carers.

Formal carers both responded appropriately and failed to respond appropriately to choking events. Considering level of awareness and appropriateness of response in isolation however, belies the complexity of all the possibilities that arise in the moment of a choking event; the mix of

different levels of knowledge, competing possible explanations for what is occurring and whether supports provided really are that supportive. In the middle of the choking narrative the need for training support for formal carers was acknowledged, however training may not be sufficient to offset what happens in the moment, and this also needs to be acknowledged.

In Nancy's story, choking identification and the response to it unravelled because of both conflicting levels of staff knowledge and the confusion caused by misdiagnosis of a choking event⁴³.

Nancy, Felicity, and Agatha

Felicity, a PCA⁴⁴, was able to identify choking when feeding Nancy, who was 95 and had dementia, her meal. She:

"...stated that Nancy was eating well at first but then she started coughing. This occurred after she had had approximately three or four mouthfuls of food. Felicity stated that when the coughing started she hit Nancy on the back. She stated that having attended a training session...on the subject of choking she knew that it was appropriate to hit the victim on the back...she saw some food coming out. Felicity...immediately called the RN [Agatha]. She did not leave Nancy for that purpose but remained with her. According to Felicity Nancy stopped coughing and was breathing but exhausted from her coughing effort, Felicity could hear a slight rattling noise in Nancy's breathing and thought it likely to be something in her throat. Felicity stated that when Nancy had stopped coughing she thought that her airway was no longer blocked" (144 finding).

Agatha (an RN) arrived and seated Nancy in an upright position. The coroner commented on how the initial successful identification of choking became lost in multiple staff being involved and misdiagnosis of what was actually happening:

⁴³ Misdiagnosis of a choking event is not uncommon (Sayre, 2005).

⁴⁴ PCA – personal care assistant

“RN...thought the deceased was suffering from a chest infection which had caused her coughing. It was for this reason she did not treat the deceased at least at first, as a choking victim...Deceased’s coughing had occurred during a meal. She was an extremely frail and elderly resident who suffered from dementia, a known risk for choking. She was on a soft diet. That fact should have been plain from the remains of the meal which would have been on the plate and which RN could easily have checked. RN should, in my opinion, have had a high level of suspicion that the episode she was confronting was likely to be a choking episode...particularly in the absence of any previous symptoms of chest infection that day” (144 Inquest).

Not believing Nancy was choking, Agatha, Nancy’s RN, explained at the inquest: *“...she did not place Nancy on her side in accordance with the [choking management] flowchart because she had not formed the opinion that Nancy was a choking victim...[She went on to say]...that if she had formed the opinion Nancy was a choking victim she did not know what she would have done.”* The coroner commented: *“This is a surprising admission given the presence of the flow chart in a number of places throughout the facility and RN’s training as a registered nurse” (144 Inquest, coroner’s comment).* Agatha struggled to appropriately identify choking and act accordingly. Felicity had had specific choking management training which at least meant she could provide initial aid. A flow chart was not supportive to Agatha. Acknowledgement of how quickly choking has to be identified and the speed with which it may need to be addressed to prevent fatality sets the context for how much has to be managed in the moment; identification of what is happening may seem simple in hindsight but knowledge of all the possibilities and elimination of those not relevant takes time. Also it has to be acknowledged that basic first aid and potentially flow charts cannot capture the complexity of choking events.

Acknowledgement of the unseen and unknown

Extended or secondary events

The social context of choking illuminates that awareness of a choking event and identifying when it is over may be difficult. A challenging aspect of identifying choking noted was the possibility that an initial obstruction as in Nancy's story might partially clear and then re-obstruct or a second obstruction may occur, leading to an extended episode of choking and response.

Roger and Tilda: Two events

Roger's story highlights that an extension or secondary event, unlike what occurred in Nancy's situation, may occur much later and without an intake of additional food. Roger, was 54 and lived with controlled schizophrenia and bipolar disorder, "...*had eaten a couple of potato pieces. Tilda, Roger's wife stated that Roger had choked on one of the pieces and she had given him a glass of water which has assisted Roger to swallow the food⁴⁵*". Roger seemed to clear the first obstruction. "*Roger then stated that he was not hungry and the dinner was put in the fridge. Roger has then lain on the couch and has fallen asleep*". Roger's change in posture may have dislodged food that had remained in the airway from the first airway obstruction: "*Tilda heard Roger snoring and has locked the house and left...[wife had to go out]. Tilda has returned...and has felt that the deceased was cold [there was no evidence that Roger had eaten anything after his wife left]*" (182 Police report). Roger's story requires an acknowledgement of the possibility that events may not resolve fully despite the person seeming to have recovered, suggesting that ongoing monitoring by the person or their carers may be required.

⁴⁵ The introduction of an additional object (fluid) could have made the situation worse but in Roger's situation apparently did not.

Anita's story: Being and not being ok

Potentially linked to secondary and extended choking episodes was the apparent returning to 'normal' and onlookers' belief that any obstruction had been dealt with, as illustrated in Anita's story.

Anita

Anita was "...having a piece of toast when she started coughing...a personal care assistant (PCA)...attended to her. PCA tapped Anita's back lightly which seemed to give her some relief. PCA asked her if she was okay to which Anita replied 'yeah'. Anita then stood up and walked towards the toilet. PCA continued serving and giving out medication to the other residents" (029 Finding). Anita, 58 and living with an intellectual impairment, brain injury and schizophrenia, died alone in the toilet shortly after from a full airway obstruction.

A number of autopsy reports pointed to how and why extended or secondary obstructions may occur in at-risk adults. The following autopsy excerpt describes one lump of food obstructing the airway (initial and only blockage) and gives an example of what is believed to happen typically:

"A firmly impacted food bolus is identified. A firmly impacted fragment of a frankfurt or sausage is identified within the laryngeal lumen extending into the trachea. Approximately 40mm of the food fragment protrudes above the level of the true vocal cords overlying the epiglottis. On extraction the entire mass measures 100mm in length. Approximately 60mm of the fragment of Frankfurt extends into the laryngeal lumen and proximal trachea. No food fragments are identified within the distal trachea or right and left main bronchi..." (062 Autopsy).

In contrast, in other stories multiple fragments were present in the airway:

"The pharynx was occluded by fragments of firm pale food containing green flecks which occupied the oropharynx [mouth and back of throat] and extended into the larynx [area of vocal cords]. One piece of food was firmly wedged within the larynx" (078 Autopsy).

Fragments of food, or food coating the structures of the airway after an initial obstruction is removed or partially removed, could dislodge and fall into a narrower part of the airway, causing a second obstruction. This phenomenon is well articulated in the following autopsy:

“...distribution would indicate there was more than one bolus of inhaled food particles. There would have been the food dislodged from the deceased’s mouth at approximately 12.10pm. There was also the bolus at the top of the airway at the time of her death, and that lodged in the bronchi. It is unlikely the bolus at the top of the airway and that lodged in the bronchi would have been in those positions at the 12.10pm when she appeared to establish a partial airway. There is a possibility, with effective airway clearance and assistance at 12.10pm, the deceased may have survived this particular incident” (094 Autopsy report).

The possibility of extended or secondary events, unreliable reporting of the problem by the victim, an assumption by carers that the victim is ‘ok’ based on their reports, an improvement but not resolution of breathing difficulties, lack of victim distress when choking, and lack of staff knowledge, are all complexities that make the identification of a choking event difficult. As one coroner counselled:

“I recommend that the Facility reinforce with its staff that in circumstances where residents are found to be in distress from coughing during a meal, staff should not dismiss the possibility of a choking episode until they have taken proper steps to satisfy themselves that the incident is not a choking episode” (144 Inquest).

Unfortunately, as seen in the stories above, this advice only covers one aspect of the challenge of identifying choking events (attention to coughing). Identifying choking events in reality belied the simple signs outlined in first aid resources (St John Ambulance Australia, 2013). In addition, the possibility that original events could extend or secondary event could occur needs to be acknowledged.

Additional complexities

Betty

Betty's story illustrates the teasing out often required to determine where an obstruction is located and what is happening; illustrating the difference between immediately life-threatening airway obstructions and those that can compromise respiration over time. Betty was 89 with no known swallowing problems recorded. She choked on a sausage. Not reported to the coroner at the time of her death, the end of Betty's story was revealed via her medical notes:

"The medical records show that this lady had choked on a piece of sausage the previous night commenting that it felt like it was stuck in her chest...At the hospital she underwent bronchoscopy [a procedure that allows visualisation of the lower airways] and gastroscopy [allowing visualization of the upper digestive tract] which showed a piece of cocktail sausage retained in the upper oesophagus [food pipe]. This was pushed through to the stomach. In addition, bronchoscopy showed a marked increase in pus in bronchi and probably inhalation changes. Her respiratory status deteriorated and she died" (031 Finding).

Betty's cause of death was listed as possible aspiration pneumonia relating to a recent episode with an oesophageal foreign body

Identification was not the only element of harm reduction that caused problems; what to do once a choking event was identified lead to a myriad of challenges that needed to be overcome.

Acknowledgement of challenges with first aid

First aid was far from straight forward in the social context of choking, prompting an acknowledgement that what might be perceived as a simple and easy response to choking was far from being so in everyday reality. Both informal and formal carers had problems with applying the first aid techniques for choking; elements were misunderstood, incorrectly performed, omitted or were compromised by unexpected challenges. The absence of

witnesses to a choking event – a negative in that aid could not be provided – was countered by problems created by multiple witnesses being present and therefore a need to organise response efforts. First aid was also complicated by the presence of more options for intervention, leading to problems with sequencing, coordination, and carers' abilities to apply multiple techniques.

Acknowledging misunderstandings, confusion and in-the-moment barriers to aid

Assessing the airway

The presence of a possible food obstruction was obvious in some stories, such as that of Maxina, who *"...was staring blankly with food hanging out of her mouth...not coughing or making any noise"* (024 finding). Obstructions however were not always visible⁴⁶. Some carers seemed to have the expectation obstructions would be obvious, and when they were not choking was dismissed as the cause of the at-risk adult's difficulties. This occurred in Zoe's story: *"Staff at nursing home were alerted...Zoe was in distress...[Staff] have attended to her and presumed that she has choked on some food as she was eating at the time"*. Staff accurately assessed clues that they were potentially dealing with a choking event, however *"No food matter was located in deceased's airway and it is therefore suspected that the deceased may have suffered a cardiac arrest. An ambulance was called..."* (166 Police report). Staff did provide appropriate aid when they called the ambulance for Zoe but they missed the opportunity to dislodge what proved to be a fatal obstruction because of an apparent misconception about a blockage being visible.

Allan was in a similar situation when his wife Phyllis, who was 65 with no relevant medical history, choked, showing a 'classic' response: *"She ate a piece of toast, at which time she suddenly grabbed her throat and chest and collapsed. Her husband went to her aid and checked for food stuck in her*

⁴⁶ Anatomically obstructions are unlikely to be visible below the oro-pharynx (back of mouth/throat area).

throat but found none. Ambulance officers attended but she had passed away” (070 Finding).

Harold and Kate

Even when the foreign body obstructing the airway could be seen, a ‘finger sweep’ (a potential element of basic first aid⁴⁷) could not be used to remove the blockage because of the at-risk adult’s physiological reaction to choking. This was a challenge for Harold’s carer Kate. In Harold’s story: “...food [was] lodged in back of the Harold’s throat, however Kate...unable to get her fingers into Harold’s mouth and remove the food due to the stiffening of his jaw. Kate has then rolled Harold onto his back and commenced CPR. As CPR took place Kate observed the food begin to dislodge, this allowed her to reach part of the food blocking the throat and scrape it out from the mouth” (227 Inquest). Sadly this did not reverse the outcome.

Blows to the back

The first aid response of back blows (a hard hit applied between the shoulder blades) was frequently applied when a choking event was recognised, but was not without execution problems, particularly in regard to where and how hard blows were applied. Frank, 47 and with an intellectual disability, was choking on a banana when his carer Gemma found him: “Gemma returned to the room to find the deceased sitting in an upright position struggling to breathe and coughing. The deceased’s carer has assisted him to a lounge chair and patted his lower back [not between the shoulder blades as required] in attempt to dislodge food” (188 Police report).

While *hitting* the at-risk adult on the back was documented in some stories, as when Geoffrey’s daughter asked her father when he was choking: “Do you want me to belt you on the back? [researcher emphasis]” (068 Police report), frequently descriptions of ‘patting’ or ‘tapping’ appeared. “The NOK [next of kin] tried to help the deceased by patting her on the back. This did not help

⁴⁷ Finger sweeps when the victim is conscious are not currently (2017) recommended in St John Ambulance First Aid Training because of the risk of injury to the first aider’s fingers and the risk of pushing the obstruction down into a narrower part of the airway.

and she called for assistance. Nursing staff attended...” (081 Police report). First Aid was provided, with “...*carer attempting to take the bread from deceased’s mouth [full obstruction] and patting her on the back*” (024 Inquest). When patting did not help there was no indication that attempts intensified, indicating that when first aid was tried but did not bring immediate results further problem solving was difficult for some carers. However, what also needs to be acknowledged is when there were reports of hitting or blows to the back they were only partially effective or ineffective in removing obstructions. It is unknown whether this could be due to carers hitting but not at full force due to concerns about the physical frailty of at-risk adults, or whether the technique failed in its own right, or some other reason. Certainly there were other complicating factors when applying aid. Physical challenges posed by at-risk adults continued to impact on the application of aid in the end of the choking narrative.

Lance, Jane and Rachel

Lance was 69 and had a history of choking. His body required his carers, Jane and Rachel, to coordinate their actions to overcome the barriers of size and strength to perform first aid: “*Due to Lance’s size Jane could not hold him and also endeavour to clear his airways [sic]. Rachel then helped sit him up and hold him while Jane again attempted to clear his airway*” (202 Police report). Jane and Rachel’s difficulties were as represented here due to Lance’s size, but what also needs to be acknowledged is that carers – both informal and formal – are quite frequently women, whose size and strength may be a further issue impacting on the ability to provide aid.

More than back blows

Descriptions of choking events also indicated that other variations to standard first aid techniques were occurring: “...*the nurse heard the deceased make a strange hiccupping noise. The nurse patted the deceased on the back but he continued making the same noise...*” Here ‘patting’ did not work but it would appear no other blows were applied. “*The deceased was then leant forward and pressed in his stomach in case he had a food*

blockage. The nurse then called for another nurse...Both nurses then leant the deceased forward again and pressed on his stomach. The deceased was then given a blast of oxygen” (067 Police report). This may be a distorted description of the Heimlich manoeuvre, but coroners’ reports frequently documented ‘Heimlich manoeuvre’ when it was used. This narration indicates confusion by the attending nurses as to the execution of both back blows and the subsequent technique which would usually be chest thrusts, lateral thrusts, or the Heimlich.

Clarification of techniques would seem a simple remedy for such difficulties, however what also needs to be acknowledged is that both formal and informal carers may be infrequently exposed to choking events. As such, even a good initial grounding in basic first aid may be distorted by time and memory. Additionally, in this study there was evidence of the Heimlich manoeuvre, lateral thrust and chest thrusts all being used – techniques that potentially aim to achieve the same effect but not all currently recommended – which indicates that first aid knowledge may not be regularly updated or people are accessing knowledge of first aid from different sources, some of which may be American-based. This may not be a problem but also may add to confusion and distortions of technique. Confusion over appropriate responses to a choking event was not only due to lack of awareness and knowledge but influenced by the setting and the additional challenges it created.

Acknowledging that more people present may not be protective

A possible advantage of a choking event occurring in an assisted-care setting rather than a private residence is the greater presence of potential responders. In some assisted-care settings encountered in the study data there were more skilled formal carers available such as nursing staff, and additional accessible aid options such as suction and oxygen equipment. However, the presence of more people and greater resources not uncommonly was associated with confusion, which undermined the execution of a coherent response to a choking event.

Michael's story: What to do first?

Michael, Carla and Felix

In Michael's story there appeared to be problems with awareness but also prioritising and sequencing the different elements of response. Michael was 45, living in an ACF after sustaining a head injury. He required assistance in performing day to day activities, including walking and eating: *"...he would often cough during meals, due to the amount of food [he] would put in his mouth at one time. A recommendation for Michael to be supervised while eating is noted in his file"*. Michael was eating in his room unsupervised. He was left a meal tray of soup, frankfurts (small sausages), mashed potato, and a dessert. He had eaten the soup and a frankfurt when a passing nurse Carla: *"...noticed Michael sitting upright in his bed with his head down struggling for breath"*. Carla notified another nurse, Felix, who then instructed Carla to get the oxygen and suction equipment while he went to get the medicine cart. It appears Michael was left alone while this was happening and no first aid, such as checking his mouth or applying a back blow, was performed. On return, Michael had deteriorated, showing signs of full or severe partial airway obstruction: *"Felix states he observed Michael's lips and nail beds were turning blue...As Felix was positioning the oxygen mask he observed Michael to take three shallow breaths and then stop"*. There was no indication that suction was applied. The police report noted: *"At no time was CPR administered to the deceased by the nursing staff or by the attending doctor"* (079 Police report). No 'do not resuscitate' order appeared to be in place. The autopsy showed total obstruction of the laryngeal opening with two pieces of Frankfurt sausage. No coroner's finding was available on the data base.

There may of course be omissions in reporting about attempts made to clear Michael's airway; attempts that having failed made CPR inappropriate. However, other stories at the end of the choking narrative suggest that there may be confusion around the juxtaposition of basic first aid and the use of

equipment when it was available, creating difficulties with sequencing the elements of aid and moving seamlessly from one aid strategy to another.

Barry and Andrew

Sequencing aid elements was a problem when Barry, 77, living with dementia, Parkinson's disease and stroke, choked on a handkerchief, RN Andrew came to his aid using equipment available. The coroner concluded that *"...handkerchief was present and partly occluding airway which became a full occlusion when sucker was used to try and relieve breathing...It is true that RN did not visualise deceased's mouth before performing the suctioning and in this he was at fault"* (159 Inquest). The suggestion here is that checking the mouth, a basic element of airway management, may have allowed Andrew to see the handkerchief, whereas the use of suction [possibly perceived as a superior technique] in the absence of a visual check made the problem worse by pushing the obstruction further down.

The availability of equipment in choking management added an element that needed to be coordinated in an overall process. In contrast to Andrew's – albeit unfortunate – use of equipment, Faye and other carers did not take any advantage of the availability of such technology.

Estelle and Faye

At times, an element that could have been helpful was omitted, as in Estelle's story when after an initial choking event her care notes reported: *"Resident then became responsive, respiration remained laboured. Returned to bed"*. In reviewing the care notes the coroner commented: *"Nor is there any indication oxygen may be useful to assist with her laboured breathing"*. In evidence, Faye the RN: *"...acknowledged the failure to administer oxygen was an oversight on her part"*. Estelle's care assistant: *"...also referred to her [having] knowledge as to the availability of oxygen but stated at the time staff were so stressed with caring for Estelle she did not think of the advisability of administering oxygen"* (094 Finding).

In some stories, even when the advisability of suction and oxygen was acknowledged, there were deficits in carer knowledge in regard to the location, maintenance, and correct use of equipment:

“RN asked staff member to go and obtain an oxygen cylinder with a suction facility from another unit. Staff member ran to the other Unit to obtain the suction equipment but the staff could not locate it” (061 Finding).

“A portable suction unit was brought to the room with the intention of using it to try and clear deceased’s airways. However the device was inoperable because the oxygen cylinder which powers the unit was empty... The centre’s automatic external defibrillator had been brought to deceased’s room... It reported no shock advised. It also indicated its battery was low [battery had to be changed]” (223 Finding).

Such failings prompted coroners to make recommendations in regard to equipment, such as:

“To provide practical (hands on) training on the checking, maintenance and correct use of emergency equipment including but not limited to policy and procedures ensuring readiness and resources of emergency equipment” (223 Finding).

The problems staff had in finding, maintaining and using equipment may be a reflection of how infrequently they are required to use such aids. Awareness may have existed, but due to lack of need not regularly updated. Given the demands on carers, prioritising knowledge and skills based on the frequency of their need may be an important part of the social context for formal carers that needs to be acknowledged.

Amy and Ruth

In some stories, techniques were inappropriately abandoned in juggling perceived priorities such as additional aid arriving, as seen in this nurse’s decision in Amy’s story. Amy was 80 years old with no medical history reported: *“Following several minutes performing CPR, RN left to investigate the whereabouts of the ambulance, carer remained with deceased... RN should not have ceased CPR to attend the ambulance and should have continued CPR until the ambulance arrived” (049 Inquest).* Problems with the

resuscitation process also occurred in Ruth's story, with the coroner opining: *"...the level of staff training and education resulted in fragmented resuscitation process"* (223 Finding).

Omissions, fragmentation, and sequencing problems were potentially exacerbated by multiple care staff being involved in a choking event; as one coronial report concluded: *"...the provision of an emergency response was limited due to ineffective teamwork and task design"* (223 Finding).

Confusion leading to 'ineffectual teamwork' was clear in the end of Malcolm's story, where aid was delayed because of role delineation and misunderstanding. In the ACF where Malcolm was residing there was a protocol in place allowing for basic first aid by extended care assistants, but those involved in the end of his story claimed otherwise.

Trudy, Ingrid and Malcolm

Trudy, the extended care assistant attending Malcolm, who was 77 years old with dementia, stated at his inquest: *"That at the time of Malcolm's death it was her understanding that she was required to immediately seek nursing help in the case of a choking patient and that extended care assistants were not to be involved in trying to relieve the resident"*. This perception was mirrored by Ingrid, the RN on duty at the time, it being her *"...understanding that extended care assistants were not permitted to give a choking resident a "thump on the back" and that this could only be done by the enrolled nurse or the registered nurse. It was her further understanding that the enrolled nurse was not authorized to use the oxygen or suction equipment"* (217 Finding).

The coroner concluded: *"The deceased's death has, in my view, clearly demonstrated serious deficiencies in the readiness and capacity of the Home's staff to properly respond to a medical emergency, particularly an emergency involving a choking resident. These deficiencies...largely centre around uncertainty among staff members of the role they are authorised to play in an emergency situation and their unfamiliarity with and/or ignorance of the Home's emergency protocols..."* (217 Inquest).

In light of struggles with basic first aid, the added availability of equipment presented additional challenges as to which available technique should be provided: when, by whom, and for how long. More options did not necessarily equate to more effective aid and this needed to be acknowledged and considered in addressing aid responses.

Acknowledgement of the need for training

Not surprisingly perhaps, coroners' recommendations relating to the end of the choking narrative reinforced proposals that focused on the need for education and orientation to emergency procedures and skill training.

Acknowledging different training needs

Recommendations about education acknowledged the context in which at-risk adults were cared for and underscored the significance of choking to the stories of carers, as illustrated in these two comments by coroners, firstly in response to a PCA's panic around a choking event: *"PCAs receive basic training which does not empower them to deal with a medical emergency. PCA's response to the critical situation is an example of how disempowered the carer can be when faced with a medical emergency"* (024 Inquest); and here addressing the overall non-emergency context of aged care settings: *"Unlike nursing counterparts in acute nursing settings, aged care staff are rarely confronted with medical emergencies. It is crucially important to train and retrain aged care staff in emergency response"* (049 Inquest).

Nursing staff have professional training and many certificated care staff (personal care assistants, support workers) in Australia have general first aid training, which includes clearing an airway, as part of their role requirement (Victorian Skill Gateway, 2017). However, addressing lack of awareness and skill deficits was complex in the social context of choking, especially in clarifying what skills carers needed and how those skills should be attained and maintained. Coroners provided multiple suggestions.

Acknowledging different ways of improving knowledge and skill

Janice's, Ian's and Ruth's stories provide some clarification on what might assist. Janice's coroner recommended: *"A written procedure guide for medical emergencies in the centre should be disseminated to all staff, including the location and use of any emergency equipment, and appropriate training provided"* (088 Inquest). The recommendation of *"appropriate training"* is perhaps key to the end of the choking narrative. It opens up an exploration of what might be required to ensure appropriate training for the carers of at-risk adults. The coroner went on to clarify: *"An assessment of a prospective staff member's first aid skills, including recognition of the symptoms of choking, should be made prior to employment and regular competence testing carried out during the period of employment as a guide to appropriate training"* (088 Inquest).

Malcolm's and Ruth's coroners went a little further, dictating the 'how' of 'appropriate and adequate training': *"It is my recommendation that the Home promptly take steps to ensure that all staff members are aware of all emergency procedures and are adequately trained in their application. It is not in my view, sufficient to merely produce written protocols and give a direction to staff that they read them"* (217 Finding). Malcolm's coroner here was addressing the issue evident in other stories, that having the presence of flowcharts for choking management was not sufficient to ensure competent application of first aid techniques. Ruth's coroner supported practical 'hands on' training for all staff to ensure appropriate training: *"All...hospital staff to attend 'mock after hours emergency response' scenario-based training... including but not limited to...ancillary staff and roles of emergency response team including team leaders and team member's roles..."* (223 Finding).

The challenges of achieving skilled technique, the sequencing of aid elements, the appropriate use of equipment and the coordination of multiple responders highlighted in the end of the choking narrative, demonstrates the need to acknowledge that managing choking events in at-risk adults is not simple. 'Appropriate training' therefore may need to address not only basic

first aid deficits but also the issues that confound such skill acquisition. Ingrid, Trudy, Paula and Helen were staff involved in Malcolm's care when he choked; questioned at the inquest into his death their responses give some insight into the tension between 'appropriate' training and staff's engagement with it.

Trudy, Helen, Paula and Ingrid: Training before and after

Trudy (PCA), Helen (PCA), Paula (EN), and Ingrid (RN) were on duty at the assisted-care facility when Malcolm choked. It was the perception of the director of nursing that staff would be able to effectively respond to a choking event: *"All staff have been trained on the methods to be used to clear an obstructed airway; and that at the time of Malcolm's death the Home had in place a written protocol stipulating the steps to be taken in the event of a resident suffering a blocked or partially blocked airway" (217 Finding)*. Staff however either did not know or did not follow the protocols, which resulted in a series of missteps. Trudy (PCA), although able to identify a choking event, did not appear to know how to competently apply first aid and nor did her PCA colleague Helen. When Paula the EN was alerted by Trudy and Helen that Malcolm was choking, she: *"...ignored the Nurse Assist Button located in Malcolm's room [and] instead tried, unsuccessfully at first, to summon an RN using the telephone [which was not the emergency communication system in place]"*. She stated she would get oxygen but *"...did not know where the oxygen was located...and it was her understanding that it could only be delivered by her if 'there is a doctor's order for the oxygen'"*. Malcolm's breathing continued to be impaired but no further first aid was provided. When Ingrid the RN was contacted she did not call an ambulance.

The staff failed to follow the protocols which the director of nursing believed they should have known. Malcolm died, and it was some time before an inquest into his death was held. At the inquest, three of the staff reported on their knowledge at the time of the choking event, what education had occurred since the event, and their current level of competency should another choking event occur.

Ingrid the RN: *"...had not read the Home's protocol upon the management of blocked airways existing at the time of Malcolm's death but she had since read the updated version and attended a day's seminar upon the subject. However, it was clear from her evidence that she did not have a clear understanding of the current protocol and in particular the need for an ambulance to be called if the obstruction could not be cleared by the initial coughing".* Trudy, one of the personal care assistants present, reported being *"...unaware of the existence of the Home's protocol for management of airways obstruction in place at the time of Malcolm's death...since Malcolm's death she has attended a 'choking course' but it was clear from her evidence that she remained uncertain of the steps to be taken to manage a choking resident...she had not read the current protocol on choking but believed that it could be accessed on the Home's computers".* Helen, also a personal care assistant present at the time of Malcolm's death *"...had not received any training or instruction upon the management of a choking resident and she was unaware of the existence of the Home's protocol upon the subject. She was aware of the existence of the updated choking protocol but 'I've only flicked through it. I haven't read it in depth'. She was also aware that since Malcolm's death staff members have participated in a course upon choking but she was not required to attend"* (217 Inquest).

At the time of Malcolm's death there was an obvious mismatch between the management's expectation of staff skills and their actual knowledge of the institution's protocols. Allowing for the possible anxiety of answering questions in the Coroner's court, the response of staff to their current degree of knowledge about choking management was surprisingly vague. All three were a part of the end of Malcolm's story, but this did not appear to prompt them to seek out improved knowledge and competency to manage choking events in other at-risk adults in the future.

While the training they received after Malcolm's death may have been poor or the protocols not clearly written, leading to continued confusion, it remains that even attendance at an inquest to explore their part in a resident's death did not apparently prompt them to increase awareness. The 'flicking through'

of written instructions provided by an organisation to protect at-risk adults and support staff after a fatality, seemed to lack the gravitas one might expect in those responsible for the care of another. While not illuminated sufficiently in this or other coroner's reports, there seemed to be phenomena occurring in the social context of choking that related to possible broader social issues such as the effect of the environment's culture on how staff perceived their roles and responsibilities, along with possible perceptions that death was inevitable regardless of what they did. Beyond the scope of this study and its findings, such broader issues may render the ideas and recommendations suggested to increase awareness and response in carers – such as training – insufficient to address what is happening for carers and care organisations, and ultimately those at risk of choking.

The end of the choking narrative showed that some carers did need training in how to identify choking and apply first aid and such skills should not be automatically assumed to be a part of the skill sets of formal carers, regardless of whether they were personal carers or registered nurses. However the end of the narrative also highlighted that in the social context of choking, recommendations around training or protocols needed to be tempered by realistic expectations of what could be expected of carers and first aid techniques. Expectations though present were often ill-defined, making it difficult to determine what was required of formal carers, as suggested in Valerie and Gail's story.

Acknowledging expectations: What more could be done?

Valerie and Gail

Valerie was 79 living with schizophrenia and obstructive airway disease. Gail was a PCA. Reporting on the end of Valerie's story, the coroner recommended: *"This case demonstrates the need for carers, in Retirement and Accommodation areas for the elderly, may need [sic] to be trained in basic First Aid, especially focusing on health and emergency issues that may*

affect the elderly” (010 Finding). When Valerie started coughing and “...tapping her chest, indicating she couldn’t breathe”, Gail, alone in the dining room, responded: “I kept hitting her on the back and try[ing] to help her. I didn’t realise she was choking on a piece of toast. I tried hitting her on the back again and it wasn’t working”. Gail then rang the ambulance service and was told to grab Valerie “...around her chest from behind under her breasts and do 5 gentle presses [application of chest thrust technique]”. Gail tried this but it did not work. The ambulance dispatcher told Gail to try again: “I went back and tried again, but it didn’t work”. Alone and with no phone in the dining room, both Gail and Valerie had to cope with Gail leaving Valerie to get further instruction. Gail then had to inform dispatcher that the instructions had not worked and Valerie had collapsed on the floor. A workman came into dining room and kept: “...‘repeating the pressing on the chest to try and dislodge what Valerie was choking on’. Gail attended to the other residents and waited for the ambulance to arrive” (101 Finding).

Not negating the coroner’s call for training, but exploring it further, Gail did identify Valerie was choking, applied back blows and called an ambulance – all ‘basic first aid’ responses. Gail did not apply the chest thrusts initially independently, requiring instruction there, but alone her first priority would have been to call an ambulance and then follow whatever instructions she was given, all of which she appeared to do admirably. The end of the choking story did show that carers needed training in first aid and that may have helped Gail and Valerie. But in the situation she was in, despite its challenges, Gail managed to apply the techniques of basic first aid and ensure additional expertise and support was on its way. This is important to note in the social context of choking in relation to expectations of both carers and first aid. Training may not change the outcome of some events; given what Gail achieved in seeking appropriate support, applying what she knew, and following up with additional aid, a question remains as to what more could or should have been expected.

Acknowledging the desire to help and care, despite problems with first aid

A critical analysis of first aid responses by both informal and formal carers identifies technical problems, including the mistakes which are further explored in the stories below. However what also needs to be acknowledged is the desire of both informal and formal carers to help; to attempt some form of aid, no matter how misguided in hindsight such efforts may prove.

Theresa and Frank

Theresa who was 89 with mild dementia, experienced difficulty breathing while eating her dinner and indicated to her husband, Frank, that she was choking on a piece of meat: *“Frank made several attempts to dislodge the piece of lamb by slapping her in the face and reaching down her throat. He did retrieve a small piece of lamb from her throat... The deceased continued to choke. Her husband then called the family G.P. to assist”* (076 police report). In the emergency situation he was faced with, Frank tried to manage. He combined an element of first aid – his version of a finger sweep – with another ‘technique’: slapping Theresa in the face, the source and intention of which is unknown, but which was a likely distressing response for both Frank and Theresa to the choking event. When his attempts failed, Frank reached out for help from his GP rather than the ambulance service who were subsequently contacted.

Ethan and his mother

Ethan who provided care for his mother, Mary (85 with no medical history recorded), went to her aid when she *“...started to cough. At first a light cough, then she showed symptoms of choking. Ethan went to get her a glass of water and when he returned she appeared to be a bit worse. She had turned a bit paler. Ethan gave her the glass of water and Mary was able to drink some of it. The water didn’t stop the cough and she began to choke more. Her son then left the room and called for an ambulance”* (072 Police report). When something feels ‘stuck’ in the throat it is a common and

perhaps natural reaction to want to wash it down; an action that can be helpful if there is no obstruction. However, introducing an additional 'foreign body' (fluid) into a compromised airway can add to the obstruction already present or be misdirected into the airway and enter the lungs, depending on the nature, severity and position of the initial obstruction. It is not a part of standard choking first aid but was frequently used as a response to choking by both informal and formal carers and at-risk adults.

Susan and Terry

When actions directly contributed to harm, consequences were serious for all. Susan (aged 90, and living with dementia in an aged care facility) *"...was being fed her evening meal by Terry [a nurse]...She was being fed custard when she [began] to gurgle. Terry gave her some water hoping this would assist with the choking. Deceased became worse and lost consciousness..."* Susan died; a review by the facility lead to *"...Terry being no longer employed by the home. His actions following the incident were not deemed appropriate" (020 Finding).*

Maxina and her carers; Glenys, Zara and Rebecca

At-risk adults eating in communal dining rooms were frequently physically relocated during choking events. Maxina's story is representative of this and acknowledges that decisions that impact on providing aid may be due to other considerations such as sparing others from watching a choking event unfold and respecting the at-risk adult's dignity and privacy, as much as more practical reasons. This sentiment is mirrored by the coroner reviewing the end of Maxina's story. The attending PCAs *"...decided to remove Maxina from the other residents in the dining room to facilitate removing the food from her mouth. They assisted Maxina to walk to the office, approximately 20 paces from where she had been seated. Maxina walked to the office without apparent difficulty..."* The coroner commented: *"Their decision to remove deceased from the dining area was made with the best of intentions for deceased and for the other residents of the facility. At that point in time it was not apparent to the PCAs that deceased's condition maybe life threatening"*

(024 *Inquest*). Given how quickly choking events can progress and the limited time available for the effective application of first aid, such sensibilities may be ill-advised, but understandable from a social perspective.

In the social context of choking, common practices such as using water as a response to something feeling ‘stuck’ when misapplied to a choking event increased the risk of harm. What can often get lost in a critique of what happened (the facts) is the human experience in the moment of a choking event, when anxiety, panic, and other considerations may play a part that go beyond a knowledge of or compete with first aid technique.

Something rarely acknowledged but imbedded in the stories outlined is what happens for carers after a fatal choking event. Consequences include the possibility, in the aftermath of police questioning, that carers recall their actions and discern that in the moment what they did may have made matters worse. Recognising and accepting that people, with the best of intentions or lack of knowledge or both will make mistakes, opens up the space for providing support to carers. Such acknowledgement can enable them to be recognised as more than just skilled or unskilled intervening agents in choking.

While the possible trauma experienced by carers in a choking fatality is not necessary the remit of a coroner’s investigation, there were comments made in the course of coroners’ cases that acknowledged such distress could play a significant part at the time of an event and in the ongoing story of carers. Stress was experienced during an event and after, as seen in the following glimpses of what choking could be like for carers.

Alistaire and Tom

Alistaire, reporting to the police on the death of his brother, Tom, who was 53 with an intellectual impairment and was now living with his family after spending most of his life in care institutions, gave a statement: “...*that during CPR...[acting on instructions from the ambulance service]...family members made efforts to locate the deceased’s pulse. Alastaire states that a pulse was*

not located at any time. Alistaire states that he cannot be sure whether this was because there was not a pulse or due to the highly stressful environment of a family member having to perform CPR on another family member” (204 Police report).

Miriam and Patsy

Stress lingered after the event for care staff. Miriam, who found 46 year old Patsy who had suffered from schizophrenia unresponsive, applied CPR. Documented briefly in the police report, Miriam’s post-event interview was delayed:

“Police have not formally interviewed or obtained a statement from caretaker of lodge [who found deceased and did CPR] at this time due to pending work commitments and her emotional state. This has been arranged to be taken in the coming days” (106 Police report).

This coroners’ report also alluded to this stress in commenting on witness statements: *“Having the benefit of hearing from Personal Care Assistants, Zara and Rebecca and to a lesser extent, Glenys who was still clearly affected by the events...” (024 Inquest).*

When Ida (061), who was 58 years old with a background of dementia and stroke and resident in an ACF died, the impact on those involved was acknowledged via a recommendation from an internal review process that bereavement support be offered by the facility in the future. Acknowledging the impact of choking on carers not only may prompt action to support them but may also be necessary to support their continued commitment to care.

Acknowledging good awareness and response: Poor outcomes

A number of the at-risk adults in this study had survived previous choking events. The judicious application of a hit on the back did clear life threatening obstructions, reinforcing the view that effective and timely first aid is the solution for choking, and that having survived one choking event, the at-risk

adult would survive subsequent episodes. One of the complexities of choking is that ‘good’ management – which might include calling an ambulance, the application of appropriate first aid, timely attendance of paramedical expertise, fast access to acute care facilities, and/or hospital treatment – does not guarantee survival.

Angus’s story: Pulling out all the stops

Angus, 84 years old and living with dementia and swallowing problems, whom we met in Chapter 5, was given inappropriately textured food by his RN, James. When Angus experienced difficulties however, James, other medical staff and ambulance paramedics were all there to reduce the risk of harm:

“Angus started coughing...James encouraged Angus to bring up any food in his mouth...Other nursing staff arrived, and Angus was given three hard whacks on the back whilst in a bent position. He brought up a small amount of chewed food...[Another RN cleared] his mouth with a gloved finger and removing a small piece of bread...after this deceased stopped coughing sat back up in his chair for about 30 seconds took a couple of breaths and collapsed forward. Suctioning was then applied but no further food particles were removed. James and the other nurse then placed Angus on his back and started CPR with air-viva and oxygen...Code blue assistance arrived from other wards and assisted with CPR...ambulance paramedics arrived and took over CPR [pronounced dead 35 mins after paramedics took over CPR]” (026 Finding).

Surrounded by expertise, fast and skilled action, Angus still died of choking.

Commenting on responses to choking events, one coroner acknowledged:

“There was no firm consensus as to the effectiveness of different forms of training in resuscitation and/or suction equipment over and above competent removal of airway obstructions prior to EAR [expired airway resuscitation], and CPR where necessary” (094 Inquest). Angus’s story was not alone in showing witnesses to choking events doing their best to meet the requirement of “*competent removal of airway obstructions*”, as the following coronial extracts attest:

“Staff [and residents] tried different methods to dislodge the obstruction without success...[Deceased had been] grabbed around waist and been squeezed [Heimlich manoeuvre]...[They] also placed their fingers in his mouth to see if they could find any obstruction...[They] hit in the chest and back area to remove any obstruction” (012 Police report and Finding).

“While on the floor the deceased has been placed on her side and given lateral chest thrusts to no avail” (096 Police report).

Analysis of the study data repeatedly showed that, in addition to the multiple errors and confusions identified, managing choking events may not be quite as simple and effective as choking first aid protocols might have us believe. Even when at-risk adults had access to advanced medical intervention, identification and management was potentially problematic.

Quentin’s story: All the bells and whistles

Quentin, at 93, lived at an ACF, and had been on an outing with one of his family. He had fish and chips for his lunch. Quentin had dementia and Parkinson’s disease, both of which had been identified as having affected his swallowing:

“He returned at 5.30 [to the ACF and] complained of having something stuck in his throat. He had been vomiting and was seen to be drooling and having difficulty swallowing. He was also having difficulty speaking and his breathing appeared to be effected [sic]. The on duty nurse contacted the on-call doctor and was advised to get Quentin to the hospital. [Ambulance conveyed Quentin to hospital arriving at 8.05pm]...8.10pm Quentin went through triage...[and] placed in treatment room...Quentin was conscious, breathing, and speaking. He was not examined by a doctor. At 9.20 pm Quentin was checked and found to be unresponsive and not breathing. Resuscitation attempts were commenced...a large slice of lemon was removed from Quentin’s throat” (205 Police report).

Quentin died in a hospital with all the necessary equipment and expertise available for identifying and managing airway obstructions.

Quentin was “...conscious, breathing and speaking” when he went into the treatment room. He had been triaged by hospital staff, a process which apparently did not detect the need for Quentin to have immediate access to a doctor and treatment. Was it appropriate for him to be left in a treatment room alone? Only the police report was available, so no further information or its interpretation is available to fill out the details of Quentin’s story. Quentin’s story however does acknowledge the physiological complexity of a choking event, such as: how choking presents; what part first aid plays or does not play in some choking events; judgements of severity; and response triggers for action. The additional tests and treatments available in hospital did not ensure survival. Acknowledging what cannot be done in the hospital setting is necessary to temper expectations of what can be done in far less ideal circumstances, where aid is often provided by not only the least skilled, but also those least practiced in responding to emergency situations.

There were other stories where the location of the obstruction created more complexity.

Carl’s story: Not straightforward obstructions

Carl did not fare well, despite access to advanced care. Carl, 89, had dementia and a history of strokes with resultant swallowing problems, and lived in a hostel. Carl “*was out at lunch when he nearly choked on a piece of meat and thereafter he attended the hospital [with shortness of breath]. The Emergency Department doctor performed a direct laryngoscopy, using lignocaine spray as an anaesthetic to the throat but could not see any evidence of a foreign material. Carl had a chest x-ray where no abnormalities were detected. He was able to drink water without difficulty so it was deemed that he was fit to be discharged...*” Hostel staff rang an ambulance when: “*The next day Carl was found blue, unresponsive and hypotensive...He was taken to the operating room and an oesophageal food bolus [chicken] was removed via oesophagoscopy. A bronchoscopy was also performed and confirmed the aspiration of food contents and saliva, and the airway was suctioned*”. Carl died in hospital seven days later. Family expressed concern that on Carl’s initial presentation to the hospital, the “...emergency

department doctor relied on Carl's belief that the food obstruction 'had passed' notwithstanding the possibility that he was still affected by the lignocaine spray used in the laryngoscopy." The coroner was satisfied that the doctor's actions were reasonable in making "...an assessment [to discharge] based upon what Carl had told him, coupled with the results of the series of examinations he had by then undertaken" (036 Finding).

Carl's family expressed concern about Carl's ability to accurately report what was happening to him, which could have been due to lack of sensation (the lignocaine spray) or lack of insight or other, possibly dementia-related, impairment. Carl was indeed not all right, but given the tests performed did not demonstrate a problem, there was little obvious justification for the doctor to continue investigating. Choking is not without its paradoxes, which are difficult to reconcile with the seeming simplicity of a 'blockage in a pipe in the machine'. Such paradoxes have to be acknowledged to make sense of the limitations of choking prevention and intervention.

The management of choking is not always simple and straightforward; even when first aid or advanced medical interventions are available and appear to be competently applied, success is not guaranteed. That said, there were many issues that arose as part of the exploration of the end of the choking narrative that challenged whether the competent application of choking first aid was or could be applied, prompting the speculation: 'Had these issues been addressed would the outcome have been different?' When Agatha failed to recognise that Nancy, 95 with dementia, was choking as discussed earlier in this chapter, Nancy's "[f]orensic pathologist commented that had choking been suspected at a very early stage and the airway been cleared promptly Nancy may have survived the incident" (144 Autopsy report). The coroner's concluding comments incorporated additional comments from the pathologist:

"However the fact remains as pointed out by forensic pathologist that deceased was an extremely elderly and frail lady at the time of her death. If these precautions [application of appropriate First Aid techniques] had been

taken by RN the outcome may have been no different although deceased's chances of survival may have been improved" (144 Inquest).

Choking is exceedingly complex, including its identification, differential diagnosis, and response both to first aid and advanced medical interventions. Appropriate care surrounding a choking event may not guarantee a good outcome; death will indeed occur in some instances. How death occurs in the social context of choking however may have important implications for care. The next section explores the findings on the social context of choking at the end of life, illuminating what may be important to acknowledge for at-risk adults and their formal and informal carers.

SECTION 3: ACKNOWLEDGING THE END OF LIFE

There is always the possibility of death when a choking event occurs, hence the desire to prevent events occurring or intervene when they do occur. However, as the beginning and middle of the choking narrative and the previous section in this chapter has illustrated, for multiple reasons – some potentially controllable, others not – at-risk adults died. The data in this study provide the opportunity to explore some of the happenings around death in the social context for at-risk adults and their carers and reflect on whether there were concerns that needed to be acknowledged and either addressed or accepted as unchangeable. This section therefore marks a significant shift in focus to a consideration of end of life and to the challenges it posed for those involved.

Acknowledging the intersection between intervention and the need for comfort

For at-risk adults in this study there was a period of time between obstruction and death during which they were conscious or unconscious. How this space was filled depended on a host of phenomena and the contexts in which they died. In this space there was the possibility of intervention, comfort care or both. At times there were tensions between these options, as choking

pushed the boundaries of what was required care from a clinical, preventative perspective, and how a choking event might intersect with decisions already in place about end of life care. When intervention failed or was not deemed appropriate, a shift in the focus of care was needed. In Malcolm's story, when attempts at intervention ceased, so apparently did care.

Malcolm

Malcolm, 77 years old, was living with dementia and with a history of oral cancer was classified as requiring the highest level of care⁴⁸ by Aged Care funding standards: *"Unable to communicate effectively...non-ambulatory and requiring assistance with all day-to-day activities"*, he was extremely vulnerable. Malcolm had swallowing problems and was fed pureed food. On the day of his death, three carers were involved in his direct care: Trudy and Helen who were PCAs and Paula, an EN. Additionally Ingrid, an RN, was indirectly involved; not being called in until the end. Parts of the inquest of Malcolm's death have already been discussed in the previous section as it related to his carers; in this segment from his story the focus is on the last hour of his life.

Malcolm, being fed by Trudy, part-way through his meal started choking. Trudy identified he was having difficulties and encouraged him to cough: *"Malcolm then had a large cough and a quantity of custard was expectorated onto the floor. At this point Trudy 'thought he'd be fine'. However 'suddenly he started going a shade of grey'. Trudy had in the meantime called for assistance. Helen [PCA] then arrived...She described him as 'not a good colour' and 'struggling'. Both Trudy and Helen were concerned Malcolm was still choking on his food"*. Despite this assertion, no further first aid techniques for removing an obstruction were applied either by Trudy or Helen: *"They attempted to stand him up but his legs collapsed under him. It was shortly after this Paula [EN] arrived"*. This was approximately 10 minutes after the start of the meal.

⁴⁸ Needing support with all aspects of daily living such as personal care, eating and nursing support.

“Paula described Malcolm as being ‘quite distressed’ she said that his eyes were fixed that he was pale and was breathing. She checked his pulse and ‘it was rapid but quite strong’ she examined inside mouth and could not see any food lodged in his throat”. It appears the absence of a visible obstruction prevented further problem solving around the possible need to clear Malcolm’s airway. Together the three women transferred Malcolm “from his chair to his bed where he was placed on his left side in the recovery position”. At the inquest the question was put to Trudy: “So, at the time Malcolm was placed on his bed, did you feel that he still needed assistance?” which she answered by saying, ‘I’d probably say no. I think by that stage he wasn’t looking very good at all and he was very, very extremely pale and just sort of gulping, gasping for breath so I think – I just think it was sort of – I don’t think anything that you could have done would have made any difference, he was going’”. The three women then left the room together.

At this point the telling of Malcolm’s story diverges into two different versions of who said and did what and when and with what rationales. The alternative versions articulated issues that have already been identified as part of the choking narrative. Issues such as fragmented first aid, competing duties (feeding others, medication rounds), not using the facility’s communication protocol, not knowing where equipment was located, not knowing the emergency protocol, when to ring an ambulance and so forth. What stands out here in Malcolm’s story however is the issue of ongoing or aftercare in choking events. Acknowledging that such aftercare may involve applying more aid or may require a shift of focus involving support for as comfortable a death as possible.

Collating the diverse witness reporting, the coroner summarised Malcolm’s situation; the end of his choking and personal story:

“It is patently obvious upon the evidence that Malcolm was seriously unwell when he was placed in his bed following the choking incident. He was then, as I have found, left alone in his room for about 15 and possibly 30 minutes without being provided with any company or support and without any serious attempt being made to

obtain proper nursing or other assistance. The treatment of Malcolm was, in my opinion insensitive, if not callous and fell well short of the standard of care to which Malcolm was entitled and which his family could reasonably have expected...When Malcolm was placed on his bed the EN was acutely aware of the gravity of his condition. Although she felt his airway obstruction had been cleared his ongoing signs suggested to her that he was either in shock, hyperventilating or about to have a heart attack. I accept that the EN may have been of the view that Malcolm's death was imminent and that nothing could be done to reverse this outcome. Nevertheless, it was, in my view, incumbent upon her to immediately ensure the attendance of the registered nurse. She failed, in my opinion, to seriously pursue this. Too, it was incumbent upon EN to ensure that a member of staff, preferably herself, remain with Malcolm until RN's arrival. This, she failed to do" (217 Finding).

The limitations of the care offered in Malcolm's story identified that choking management may need to address the signs of successful and unsuccessful obstruction removal, the monitoring of possible secondary events, and the management of other health issues that may be triggered, such as shock; all concerns associated with intervention. Malcolm's story however, also challenges in the broader social context of choking, and in the event of the failure of intervention, how end of life care is provided. This extended context of how death is managed in choking returns us to the concept of quality of life (discussed in Chapter 2) and what constitutes compassionate end of life care. In Malcolm's case this may have been as simple as making sure he did not die alone.

The end of the choking narrative highlighted some tensions and variations in type and amount of care that might be offered or needed to address choking and end of life concerns. Care could be focused on intervention or the acceptance of death. The stories of Benjamin, Charlotte and their families showcase how these two seemingly disparate focuses of care came together in the social context. Extensive rescue efforts were made at the scene and in hospital before circumstances prompted questions about the need to shift the focus of care.

Benjamin

Benjamin was 88 with a history of Parkinson's disease when he choked at home:

"...family have commenced CPR and called for an ambulance. The ambulance [paramedics] arrived and continued CPR. A second ambulance attended and [paramedics] removed a large piece of fruit from the deceased's trachea. The deceased then required defibrillation was intubated and ventilated...transported to the intensive care hospital...the deceased was connected to life support to assist with his breathing...He had not regained consciousness and [was] not responding neurologically...the deceased was taken off life support with permission of family members" (080 Police report).

Natalie and Charlotte

Charlotte's daughter Natalie was hosting her child's birthday party when Charlotte, 84 with no relevant medical history, choked. Natalie, family and friends responded with first aid; Natalie performing CPR while waiting for the ambulance to arrive:

"At hospital the family was advised Charlotte had suffered from severe brain damage as a consequence of the incident. A Glasgow Coma Scale [GCS] was conducted on Charlotte which resulted in a response of 4 [out of a possible 15 and indicative of severe cognitive impairment (Teasdale, 2014)]. There were no signs of improvement...Charlotte's family were consulted whether to leave Charlotte on the respirator or take the tube out and let her breathe on her own. The family discussed it and agreed Charlotte would be extubated and was not for resuscitation in the case of cardio respiratory arrest" (225 Police report).

Charlotte died the next day. For both Benjamin and Charlotte, the loss of consciousness that triggered advanced medical intervention meant they were likely unaware of the extensive efforts attempted to keep them alive. For their families and the formal carers involved, efforts to maintain their lives proceeded over many hours, culminating in potentially difficult decisions around prolonging life artificially and allowing death to occur.

Decisions about interventions – whether only select interventions could be applied, how long interventions should be applied and whether they could be withdrawn and under what conditions – occurred across the various environments in which at-risk adults choked. How decisions were made and implemented varied, illuminating a range of concerns relevant to at-risk adults and their informal and formal carers. Some of these concerns were addressed in certain situations for some at-risk adults, but exploring the social context illuminated that other concerns required mechanisms in place in order that they could be acknowledged and addressed.

Acknowledging concerns and end of life care for choking in the community

End of life and associated decisions could happen without warning, and in a short space of time informal carers could be catapulted into highly stressful, challenging situations. What follows are insights into decisions around end of life care for choking in the community; ‘the community’ here representing situations outside the hospital context, where perceptions and availability of advanced intervention may be different from a more acute care environment.

Fiona and Nathaniel’s story

When Fiona and her father Nathaniel went for a walk and stopped at a café for lunch, Fiona had no idea that before the meal was over she would be making potentially one of the most difficult decisions of her life, to be later documented in a police report:

[At café with adult child] “Deceased ordered a steak, and choked on a large piece of the steak. Deceased tried to swallow it using water at his table but collapsed in his chair. CPR conducted but unable to revive him. Ambulance attended and CPR continued until family decided to cease” (167 Police report).

Nathaniel was in his late eighties and lived in a hostel; he had no documented medical history associated with swallowing problems. Fiona’s decision to cease CPR may not have been a ‘meaningful’ choice about

prolonging or not prolonging her father's life, in that it may have been obvious to everyone that Nathaniel had died. It may however, have been a profoundly considered, compassionate decision, or a deeply traumatic one, or perhaps all of these and/or others still.

Fiona was not the only family member called on to make an in-the-moment decision in regard to withdrawal of intervention efforts. Genevieve also had to make such a decision but in quite a different context, drawing attention to the possibility that Genevieve may have been being asked – in confirming a care decision – not only to support her mother but also the formal carers involved at the end of her mother's life.

Genevieve and Bridget

Bridget, 90 years of age, had dementia and acute renal failure. She had a 'do not resuscitate' (DNR) order in place. She was having lunch in the ACF where she resided when she *"...appeared to be choking on her food and staff immediately removed her to a nearby room where they attempted to clear the airways blockage...[Bridget's] daughter, Genevieve was apprised of the situation per phone and she stated that she did not want her mother resuscitated if she stopped breathing...[Paramedics attended]...Staff and ambulance officers administered emergency procedures but they were unable to dislodge the food and Bridget stopped breathing. She was not resuscitated"* (043 Police report).

One can only imagine what it must have been like for Genevieve to be contacted as her mother was choking and be asked about limits of treatment. We do not know what contact arrangements she had with the care facility around Bridget and a possible health crisis. She may have drawn comfort from knowing and being 'connected' by phone at the time of Bridget's death. A DNR order was in place however, so was it necessary for her to be contacted? Family decisions around resuscitation are not necessarily easy ones; is it appropriate when such planning has been addressed to ask families to make the decision again in the moment? Was there confusion among staff as to whether a DNR order related to choking? Had the

possibility of choking in someone with dementia been discussed in the context of the initial placement of the DNR order? We do not know the answers to any of these questions. Phoning Genevieve may have been a respectful, kind, pre-arranged act, or an act that created unnecessary trauma by directly involving Genevieve in the immediacy of her mother's death.

Fiona and Genevieve's stories highlight that families may be called on to make resuscitation decisions as choking events are occurring. Awareness and acknowledgement of this as a part of the social context of choking is important in understanding the pressures on all carers and how they may be better supported. In community settings, formal carers and assisted-care organisations may want to confirm both the currency of DNR orders and their relevance to choking. Jim's family was not contacted, but his DNR order was confirmed while basic first aid – up to the point of resuscitation – was being applied.

Jim

Jim was in his 60s with a medical history of brain damage, schizophrenia and possible strokes. Living in an ACF, Jim had a DNR order in place. When he choked, attempts at first aid were applied, as was oxygen. A nurse stayed with him while a:

“...second nurse phoned Jim's doctor's clinic and a doctor at the clinic confirmed the no resuscitation order. The nurse then phoned the ambulance...Upon arrival the paramedics could find no pulse on the deceased. No further treatment was administered” (067 Police report).

Eloise

Unlike Jim, Eloise, 86 with no dysphagia-related history, lived at home, however she also had a DNR request in place. What her story highlights is that, in a resuscitation situation, access to an advance care directive may not be possible, and therefore CPR may be performed at the scene:

Eloise had *“An advance health care directive which stated that she was not for active resuscitation in the event of cardio-respiratory arrest”*. The directive was on record in her patient notes at her local hospital, prompted

by a history of major heart issues. When Eloise choked at home: *“Her son called ambulance but was unable to provide CPR [reason not documented]...[ambulance administered shocks, medication and intubated]...In ICU she displayed poor neurological signs, consistent with severe hypoxic brain injury...There was no evidence of neurological recovery over the following two days”*. Based on her directive and *“In discussion with the family, she was extubated...and passed away shortly after extubation”* (206 Autopsy report).

Eloise had to wait for her advance care directive to be enacted until she reached hospital and her wishes could be accessed from her medical notes. In the interim, active resuscitation was the default response.

These stories illuminate possible points in active choking intervention when decisions may be enacted and intervention may be ceased. In Fiona’s story after CPR had been commenced, in Genevieve’s and Jim’s stories when CPR would normally have commenced, and in Eloise’s story only after she reached hospital and her wishes could be confirmed.

In the social context of choking represented by the above data, the presence of advance care directives or DNR orders were respected, though confirmation from family or the at-risk adult’s representative (in Jim’s story his doctor) were either believed to be required or sought by formal carers to reinforce a shift of care from intervention to acceptance of death. However this seemingly clear connection between choking and DNR requests was not automatic; some stories presented anomalies in how choking was viewed in the context of other health conditions and associated end of life care plans.

Oscar

Oscar, 85 with Parkinson’s disease and cancer, was receiving palliative care in an aged care facility and had made his decisions about care known, which included restrictions on intervention. *“...[D]iagnosed with terminal cancer”*, Oscar’s life expectancy was given as no longer than eight weeks at the time of his choking event: *“...he had advised doctors and next of kin that he did not want to be resuscitated whilst he was in palliative care”*. While *“...being fed by the [ACF] nurse...It appeared that the deceased began to choke...The*

nurse attempted to resuscitate however was unsuccessful...” (071 Police report). Choking appeared for the nurse on duty at least to be somehow exempt from the comfort care normally associated with palliative care and Oscar’s end of life decision making. The nurse may not have been aware of Oscar’s wishes, which is a broader issue for at-risk adults, however such confusion in regard to how choking needs to be addressed would not be surprising in the context of the data analysed here. Dorothy was also in receipt of palliative care in her ACF, and her story details some of the events that follow choking deaths which affects how this care approach may be perceived.

Dorothy

“A palliative care plan was put in place” for 95-year-old Dorothy who had multiple health issues, including an oesophageal stricture and a history of choking events. She was eating her TM breakfast and being supervised by a nurse from across the room when *“...she regurgitated an amount of her food. She was struggling for breath and her colour was poor. Given suction [sic] and oxygen, doctor and NOK notified, no resuscitation or ambulance called”*. Dorothy was given care more aligned with comfort in recognition of treatment limits; she was administered suctioning and oxygen but not given back blows, or had chest thrusts applied in her final moments, nor was resuscitation attempted.

Not reported initially to the coroner at the time of her death – choking being a reportable death – her case was later reviewed. The coroner concluded: *“Having regard [sic] considered the efficacy of care and treatment provided to Dorothy I find appropriate steps were taken to address her eating problem and would not necessarily conclude her management was other than reasonable and appropriate in all the circumstances”* (025 Finding). The coroner’s comment is particularly interesting in that it highlights, due to Dorothy’s death resulting from choking, despite a palliative care plan being in place, an assessment had to be made of care prior to and at the time of the choking event. The ‘care’ which involved a lack of ‘normal’ intervention for

choking was deemed appropriate, given Dorothy's broader circumstances. This acknowledges that when individually assessed, a purely death-prevention response is not always seen as appropriate. It also however highlights the tension between choking viewed as an 'accidental death' requiring intervention (and police investigation) and choking as a consequence of two underlying risk factors for death (dysphagia and advanced age), and in the context of a decision for non-intervention. They are potentially difficult perspectives to reconcile and a concern that needs to be acknowledged in determining what might be appropriate care in the social context of choking.

The form of care appropriate in response to choking for at-risk adults given their individual situations was challenging. None of the DNR orders or advance care directives were reported to have been put in place because of choking, making it difficult at times to tease out what was required to honour end of life wishes and care in the event of a choking episode. One of the concerns here was whether care that was appropriate for and may have potentially reversed a choking event might be withheld because of confusion around the interface between choking and more broad directives around end of life care. Certainly there was the suggestion of this in Duncan's story, which was confronted head-on by Estelle's coroner in regards to hers, both discussed below.

What at-risk adults may want for end of life care, what formal carers may perceive their wishes to mean, and the implications for care for those choking, were concerns that filled the space between airway obstruction and death. Duncan's and Estelle's stories explore some of these perceptions and their possible consequences.

Duncan

When Duncan who was 90 entered an assisted-care setting, he made decisions about his end of life care: "...staff stating that the deceased had requested no aggressive intervention when he was admitted to the lodge made [sic] no resuscitation attempts" (001 Police report). Duncan was having

lunch when other residents alerted staff that he was having difficulty breathing: *“Staff members were alerted by other residents...that Duncan was having trouble breathing. Veronica, a personal carer, conveyed Duncan to his room...and checked his airway, which was clear. No pulse was detected. Staff then called the ambulance and a doctor” (001 Finding)*. A nurse attended and noted that Duncan had died; the ambulance was cancelled. Duncan did not receive first aid up to the point when CPR would be performed. This may have been due to his carer not realising he was choking because the obstruction could not be seen, or the speed with which he became unconscious. The statement by carers to police indicated that this lack of intervention such as a hit on the back may have been influenced by their perceptions of what he would have wanted. A hit between the shoulder blades may have relieved the obstruction and Duncan could have continued with his lunch or it may not have helped at all. This is a possible tension in the application of broad statements in regard to care and the window of opportunity choking affords for a potentially ‘easy and quick fix’ to the problem. Estelle’s situation was rather more involved, with her coroner questioning more fully the execution of intervention, comfort care and advance directives. Different perceptions of Estelle’s intent, along with who, when and how such wishes should be enacted, were illuminated by her story.

Estelle

Estelle, 85 years old with a history of a prior choking event, was a widow residing in an ACF. Eight years prior to her death she completed and signed in front of two witnesses an expression of her wishes (referred to as ‘her card’) in regard to end of life care, a copy of which she gave to the facility when she became a resident. Like Duncan’s, Estelle’s wishes broadly stated (without reference to specific interventions) that she did not want to be kept alive by artificial means if circumstances occurred that left her *“...without reasonable prospect of recovery...incapable of rational existence...” (094 Inquest)*.

There were general choking management procedures in place at the facility, some elements which were followed by staff but not all. This partial observance during Estelle's choking event led the coroner to comment:

"In reality I believe the staff...were capable of complying with those [omitted] steps but speculate they were not followed as a result of some confusion in the perception of the meaning of the deceased's [expression of wishes] '...card'. I also believe the 'signs' and 'procedures' headings for total airway obstruction were capable of being competently undertaken by staff at the time. Between them there was certainly the training to undertake resuscitation in an emergency situation" (094 Inquest).

The coroner was implying that, given their failure to follow procedures, staff consciously or unconsciously did not perceive choking in Estelle's particular case as warranting active intervention past a certain point. Given previous stories of steps being missed in applying aid this may not be the case, nevertheless the coroner's view was potentially reinforced by Estelle's two carers, Pam and Rita, who specifically referred to their awareness of the "the card" in their statements to the investigating police. At the inquest, Pam: *"...admitted she believed the deceased, after the slap on the back and the expulsion of a food particle would either recover or slip away [no further back blows or other techniques were applied]"*. Specifically, CPR was not applied when Estelle lost consciousness. The coroner did not see this as *"...a lack of care but rather an attempt to comply with what the carers believed to be Estelle's wishes"*. The coroner however did not concur that it was Estelle's wish, given the wording of her directive. Embedded in Estelle's story was the missed opportunity prompted by a previous choking event to explore her wishes more fully. Of particular significance to the social context of choking was the coroner's more general comments on *"...appropriate action when an unexpected medical emergency arises"*.

The coroner recommended that directives such as Estelle's should be ignored by carers at the time of a medical emergency: *"The emergency should be dealt with until such a time as stability has been achieved and the decisions with respect to ongoing care be left to the patient, their medical*

advisors, and family members...I accept, without specific direction in this area, the situation may be confusing for carers wishing to comply with the deceased's perceived wishes as to her quality of life...Should the law change, so correspondingly can the policy and procedure, though I doubt it would ever be reasonably be [sic] a decision made during the course of a medical emergency in progress" (094 Inquest).

The coroner's recommendation seemed to acknowledge Estelle's wishes and provide direction to carers by arguing that every intervention available should be applied, as it was 'an emergency'. However, there are a number of tensions identified in decision making at end of life and specifically how such decisions are interpreted in choking that need to be acknowledged. As seen in other stories, decisions made prior to and during a choking medical emergency do occur and have not drawn comment or specific recommendations from other coroners. Estelle's wishes however, were more amorphous than some directives, where an instruction to not be resuscitated was stated specifically. Even then clarity is needed as to whether this applies to a choking event. Clinically, someone with swallowing or eating problems is at risk of choking. Those experiencing choking events are manifesting that risk, as in Estelle's case. Choking *is* a medical emergency, but in at-risk adults perhaps should not be considered an 'unexpected' one, particularly as preventative strategies do not guarantee the avoidance of such events. In this respect it is no different from someone with a known heart condition considering their quality of life options and making certain decisions about what medical treatments they may wish to have or to refuse should a cardiac event occur. Certainly in keeping with the comments of Estelle's coroner, regardless of what a directive might indicate, very clear guidance needs to be given to carers as to their role, particularly in regard to managing choking in the presence of an advance care directive.

Acknowledging concerns and end of life care for choking in the hospital setting

Twenty-five percent of at-risk adults experiencing a fatal choking event in this study were transported to hospital, where they subsequently died. Access to advanced medical expertise and equipment, combined with the clear presence of brain hypoxia⁴⁹, presented both professional carers and family members with the challenge of having to make end of life decisions from a slightly different perspective; that of prolonging life or likely prolonging dying. While decisions about withdrawal and refusal of treatment were most frequently made consultatively between families and medical staff, not all decisions were prompted by or discussed with family, alerting us to the diversity of the social circumstances of some at-risk adults, such as seen in Ginny's story.

Ginny

Ginny, 41 was living with cerebral palsy and an intellectual disability. After Ginny's choking event she was admitted to the critical care unit: *"She was commenced on sedation and ventilated. It appears the patient was subject to guardianship provisions and the Public Advocate's office was contacted with respect to her management and clinical decision making...She remained febrile and was fed via a nasogastric tube. She required ongoing sedation with midazolam and morphine"* (030 Finding). There was no neurological improvement when sedation was removed for 72hrs and consequently her care became palliative. Medical directors, public guardians, family members and at times at-risk adults themselves via advance care directives, were all potentially involved in decision making between airway obstruction and death. What is marked about dying and end of life care in the hospital setting is its contrast to the near immediate deaths from choking illustrated in other stories; death from choking in hospital could be a long, drawn-out process.

⁴⁹ Lack of oxygen to the brain.

The following brief elements, gleaned from multiple stories, focus on the manner of dying from choking in an acute hospital setting. They capture the often key moments when a focus on intervention in choking shifts to a focus on quality of life and comfort care.

John

John, aged 74 with no medical history recorded and previously residing in a nursing home, died approximately three hours after he choked and was transported to hospital. Instructions for care were already in place but were confirmed by his family: *“His respiratory status continued to deteriorate in the emergency department. His GCS was 3. Next of kin called and clarified that he was not for intubation or resuscitation and he died in emergency department...”* (161 Police report).

A decision about John’s end of life care had already been made prior to his choking event; without active treatment he died on the day he choked. For others dying was extended over days, weeks and even months.

Wendy

Wendy was aged 56 and living with an intellectual disability, who died seven days later after she was *“...admitted [to] Intensive Care in serious condition. She did not regain consciousness and her condition did not improve. She was transferred to Palliative care unit for palliative management [7days after admission]...where she remained until death [died on day of transfer]”* (016 Finding).

Isaac

Active treatment continued for Isaac, aged 54, who lived with an intellectual disability and mental illness, who died 14 days after he choked: *“Isaac was intubated but had sustained hypoxic brain injury and was ventilated until he died”* (035 Finding).

Lawrence

Lawrence died three months after choking; no medical or residential history reported in coroner's documents: *"This 90 year old man choked on food at a restaurant and suffered an hypoxic brain injury. He subsequently died from this three months later [in hospital]" (053 Finding).*

Three hours to three months; the dying process of choking differed depending on different factors such as DNR orders in place prior to obstructions, cessation of active treatment, and 'letting nature take its course' with or without withdrawal of active treatment.

In some of the stories above, decision making may have been fraught, while for others the knowledge that all medical intervention possible had been tried may have eased the burden, at least for those left behind. For some families the presence of decisions made prior to choking may have made subsequent decisions more straightforward. However, what all these stories illustrate is that informal carers may well have to make decisions about resuscitation, long-term ventilation, and tube feeding; either electing to refuse or withdraw such care measures. For some families this will extend to additional decisions, as they did for Tania's family.

Tania

Tania was aged 62, living with mental illness when she choked. The end of Tania's choking story meant that other individuals could potentially continue with their life stories. This however was reliant on Tania's family being able to make an altruistic decision at the time of coping with Tania's death:

"...assessment completed...and confirmed brain dead. Family present.

Family agreed to organ donation to be done" (065 Police report). Tania's story acknowledges the possible extent of the decisions informal carers may have to make at the end of a choking story.

This section has so far recognised concerns around the need to consider both intervention and comfort care, thus exploring dimensions such as what interventions may or may not be applied, the timing of interventions and

potential shifts in care focus, who makes decisions about the focus of care, and when such decisions are made. In light of the acknowledgement of these aspects, two further acknowledgements will be briefly presented.

Acknowledging support for formal carers

Edgar who was 79, was living in a mental health facility suffering from dementia and Parkinson's disease. While not in an acute hospital setting, doctors were part of the assisted-care setting where Edgar was living. What is telling about this story in comparison to other stories set in the community was that formal carers were seemingly highly supported to respond optimally to the challenges of choking and care options. They were highly skilled, in sufficient number to allow for multiple aid options to be accessed and addressed, and appeared to work as a cohesive team, with role clarity along with an awareness of the need to intervene but within pre-determined limits:

"Due to the severity of his Dementia and his [other] multiple and severe medical problems, Edgar's family elected to provide him with palliative care". At the time of his choking event: "...Edgar was stood up by nursing staff who slapped his back in a thrusting upwards motion in an attempt to dislodge food. A duress alarm button was activated. Nursing staff then moved behind Edgar and put arms around his chest area and pressed in a further attempt to dislodge the food. At this stage Edgar did not display signs of distress or gasping for breath; his body was limp and his skin complexion pale. He was then placed onto the floor onto his side and lateral thrusting movement was used in a further attempt to dislodge the food. The Clinical Nurse Consultant [CNC] attended the area and cleared Edgar's mouth; a large quantity of food could be felt in his throat. CNC ordered an oxygen cylinder, ambulance personnel to attend and 000 [emergency number] was also dialled". Two doctors arrived and "...suction was used to remove some food from Edgar's mouth but the remainder was too far down his throat to allow for normal breathing. At this time he was observed to have cyanotic lips, lying very still on his back". Staff "...worked on him for approximately 15 mins...the deceased had a DNR in place a decision made by his wife some time ago, for this reason CPR was not attempted" (222 Finding).

Edgar was pronounced dead by one of the attending doctors before the ambulance arrived. The space between obstruction and death was not one of confusion in Edgar's story; unlike that seen in many others. It is important to acknowledge that based on the data, faced with a similar scenario, very few formal staff had the environmental supports present in Edgar's story.

Acknowledging an underlying support for all those involved

The final acknowledgement of particular note in the end of the choking narrative was the potential importance for at-risk adults and informal and formal carers of the need for advance care planning and the recognition that choking may need to be specifically considered in that process. Choking is a life-threatening event; because of the perceived ease of first aid it may be viewed as reversible and therefore not considered in the same way as other life-threatening events such as heart attacks or strokes. However, it shares some of the effects and outcomes of these other potentially catastrophic events. Choking can lead to brain damage, increased disability, and it can be fatal. One of the elements used to help prevent these outcomes is resuscitation, which has varying success rates (Cadogan, 2012). In the event of subsequent brain damage in a non-fatal choking event, artificial ventilation and tube feeding may also be options used to prolong life. The study findings illustrate that those involved in the social context of choking may also be faced with many of the circumstances and decisions associated with other life-threatening medical emergencies.

Generally in Australia, those with life-limiting illnesses and medical conditions that may affect their decision making are particularly encouraged to document their wishes in regard to both end of life care and interventions that may prolong a life that they anticipate would not be meaningful to them (Carter, Detering, Silvester, & Sutton, 2016). The decision making power is thereby being placed more firmly in the hands of the person whose biological and biographical life may be threatened or by proxy their substitute decision maker. As identified in the 'setting the scene' section in Chapter 4, those with

conditions that impair cognition appear more likely to experience fatal choking events. These at-risk adults in particular may need to consider the possibility of choking and plan for how they may want such events managed while they still have capacity. Similarly, an acknowledgement of choking as a potential cause of increased disability and death needs to be considered by both assisted-care organisations and formal carers, so that they have time to consider what needs to happen in the space between airway obstructions and death, including the likely ramifications for both them and at-risk adults.

Choking events will happen in situ, in the moment, potentially reach a crisis point within minutes, and with potentially the least qualified formal carers or informal carers as the first responders. Decisions about QoL and the wisdom of prolonging life using artificial means may well have to be made.

Acknowledgement of the concerns of all around end of life and death is important in the social context of choking.

Summary of Sections 1 – 3

The end of the choking narrative highlighted multiple issues of importance to providing support to at-risk adults and their carers in the social context of choking; issues that need to be acknowledged and where possible addressed. The first fundamental issue is whether carers can adequately identify and perform basic first aid when a choking event occurs. Some carers – both informal and formal – both lacked awareness of and struggled to respond to all the challenges presented by a choking event. Some of the identified reasons for this were: non-existent or inadequate training; carer stress at the time; the physical or behavioural responses of the at-risk adult; environmental challenges such as unclear directives or multiple competing demands in assisted-care settings; or some combination of these factors.

Another major issue was the coordination of first aid techniques and other interventions available. According to the stories portrayed in this study, important treatment steps were not uncommonly missed, and there were problems with how first aid techniques interfaced with such technologies as

suction and supplemental oxygen to provide a comprehensive rather than disjointed response. Additionally, there seemed to be the perception that choking was a solitary, mono-causal event and if any obstruction was removed using a first aid technique the event was 'over'. The apparent ease of using a first aid technique 'successfully' possibly masked the need for ongoing monitoring of the airway (for the possibility of secondary events) and repeated application of techniques if breathing was still impaired.

There are also issues relating to how at-risk adults die. While all of the issues above might be amenable to improvement, there was also evidence that even when everything that could be done was done, including access to advanced medical intervention, adverse events including prolonged ventilator support and death itself were still very real choking sequelae. Such evidence highlights that death from choking needs to be acknowledged as a distinct outcome with associated needs for carers. Acknowledgement is required so that such needs can be identified and support provided to assist at-risk adults and their families prepare for the possibility of end of life decision making if they wish it, and/or to provide support to both informal and formal carers to cope with such an event and its aftermath.

A final acknowledgement needs to be made of the special position choking has as a cause of death. Like all deaths there is an aftermath. The aftermath of a choking fatality can be particularly difficult for carers because of the need for coronial investigation. Such an investigation is a part of the social context of choking. One of the reasons coroners investigate choking deaths is because they are considered unexpected deaths. Clinically, choking and its potential outcome of death are not unexpected in many at-risk adults, or should not be considered so given the combination of risk factors that may be a part of their condition, in addition to considerations (such as the opportunities for eating pleasure) that make the reduction – let alone elimination – of all risks impossible or inappropriate.

A tension therefore exists between the important role coroners play in identifying where care might be improved to help the reduction of choking

deaths, and the acknowledgement that prevention is an ideal that, over 250 years and because of the complexity of choking, has not been achieved. Given that choking generates so many fears, the additional fear that may be generated by coronial investigations needs to be acknowledged and sensitively handled. Coronial inquiries can perpetuate the belief that all known or suspected risks can be controlled and prevention achieved, potentially leading to highly restrictive care practices. In regard to this final acknowledgement it is perhaps important to note that, having analysed so many coroners' reports in their entirety, coroners do seem to have insight into and be sensitive to much of the social context of choking and the limits of prevention (perhaps best illustrated by none of the choking deaths occurring in an at-risk adult's home being required to go to inquest), as well as the need to temper risk reduction if strategies to that end create inappropriate burdens on the at-risk adult. Coroners displayed a depth of understanding of the needs of at-risk adults and the associated pressures on carers which may not normally be attributed to their role, with its potential to intimidate.

In conclusion, all three key categories – awareness, response and acknowledgement – wove through the social context of choking, illuminating its complexity and wide impact. The next section draws together these themes under the core category of support that was the foundation for the theory of care offered by this study.

SECTION 4: A THEORY OF CONSIDERED SUPPORT

The theory being proposed by this study is one of *Considered Support*.

The aim of this study was to explore the social context of choking and its implications for care. To this end, the methodology of grounded theory was applied with the objective that in exploring data around the social context of choking (coroners' reports) a theory would emerge that would illuminate care practices. My hope for an expanded view on care – that is, expanded beyond choking prevention and rescue – was founded on my experiences as a speech pathologist. My experiences suggested that current clinical practice

(focused predominantly on prevention of choking through the identification of choking risk factors and their control) did not always address the needs that arose for some at-risk adults or their informal or formal carers. My access to the study data enabled me to explore this possibility at depth.

The use of grounded theory in this study both illuminated some of the social context of choking and highlighted its challenges. Individual choking accounts as represented in coroners' reports were deconstructed into fragments. These fragments were labelled and grouped within an overarching story and then compared with the next account and its fragments. As substantive categories formed and were compared in and across accounts, more categories emerged; initial categories collapsed into new ones and relationships between categories and category dimensions began to emerge. As relationships and dimensions were compared, categories emerged that were more conceptual in nature; their comparison led to the emergence of higher level abstract categories that reflected and condensed previous categories. Through this ongoing analysis, three higher order key categories emerged from the data that were significant to the social context of choking and had implications for care.

These categories were *awareness*, *response*, and *acknowledgement*. These conceptually represented the many challenges at-risk adults and their informal and formal carers faced in living with the risk of choking and its expression in a choking death. These challenges were encapsulated within the categories of: being actively alert and attentive to the concerns choking presented (awareness); being able to act on those concerns as they arose (response); and being able to recognise, appreciate and accept all concerns (acknowledgement), as experienced in the social context of choking.

The reconstruction of individual choking stories into an overarching story of the social context of choking (broadly represented chronologically in its component parts), acted as a further level of comparative analysis from which a final core category emerged which captured the content and dimensions of the three key categories: the core category of *support*.

‘Support’ was conceptualised as ‘aid or help’ but also as ‘holding up or sustaining’. This was to capture the breadth of impact of choking in its social context, that being a context inclusive of elements far beyond the dominant, traditional, clinical-contextual conceptualisation. There was an inter-relationship between at-risk adults and their formal and informal carers. Awareness, response, and acknowledgement were important to all those touched by choking and all aspects of concern identified in the social context. At-risk adults might need ‘aid or help’ (via awareness, response or acknowledgement), but the challenges of providing this aid or help recognised that carers had needs independent of the at-risk adult and may need ‘holding up or sustaining’. Not unlike the palliative care model, where not only the person dying but their family are considered in the provision of care (Hudson, 2003), the social context of choking indicated that a similar notion might be needed in the area of choking, but one that would also actively include formal carers.

In reflecting on the different content concerns and dimensions of the key categories and their relationship to support, there appeared to be something missing from the conceptualisation of support as a theory. ‘Support’ seemed to embody the aspects of management and control which are a part of the clinical theory of prevention and build on that, with the acknowledgement of concerns that fell outside the possibility of prevention and intervention. It was broad enough to encapsulate what might be missing from a care perspective in the social context of choking and direct focus to what might be needed. However there remained an elusive aspect; a qualifier or elevator that was associated with the core category and the key categories which initially evaded my efforts to identify.

This aspect finally emerged from the data as I asked myself what this journey had meant to me as a care provider in the area of choking: Having immersed myself in the social context of choking via the process of grounded theory, what had emerged for me; how did I now consider choking? What did I consider would be important to an at-risk adult? What consideration would I give to those around the at-risk adult? Emerging from the exploration of the

data and these questions was the missing conceptual aspect to the core category of support. In the new theory being proposed by this study, it was necessary that support be *considered*.

When exploring the meaning of the word 'consider' and if it would adequately represent what I was seeking in describing the theory, I encountered much around its etymology that I found intriguing. While not perhaps the most exalted of literary sources, the following definition synthesises much of what I was reading and confirmed 'considered' as the most apt adjective for support in the choking context. Originally, 'consider' was something you did:

...with your eyes rather than brain. Latin *considerare* meant 'to observe or examine something', but had an earlier meaning 'to observe the stars' and was based on *sidus*, 'a star or constellation'. The earliest meaning of its English descendent consider was 'to look at something very carefully', but this soon widened to the notion of thinking carefully about something (Reader's Digest Australia, 2008).

The social context of choking presented a constellation of concerns; concerns which had implications for care. 'Looking' at the social context of choking, awareness of the 'constellation of concerns' around it was not enough; its complexity and the inter-relationship between concerns and the multiple people engaged with them requires one to think carefully about them. Responses to concerns need to be considered; well thought out. These concerns, who is affected by them, and who favourably or unfavourably influences them, have to be considered and acknowledged. Finally, extending the word derivation, consideration is required for all those touched by choking, whether it be at-risk adults, family members, formal carers, bystanders, assisted-care organisations as a whole and even speech pathologists and other health professionals. Choking is a confronting topic with many consequences.

The theory of 'Considered Support' is a substantive theory. It acknowledges, includes and builds on the extant theory of prevention (and intervention) but proposes that, based on the social context of choking illuminated in this

study, considered support is a more meaningful approach to addressing the complexity of choking and the needs of those touched by it.

The final chapter

The final chapter summarises the major concerns identified in the exploration of the social context of choking. It contains a discussion of the theory proposed by this study; how it includes but expands on the current theory of choking care, and connects to other approaches and theories already being enacted in the care landscape. It also identifies the study limitations, provides an example of how the knowledge gained in the study is being applied within a clinical care context, and finally proposes recommendations for future research.

CHAPTER 8: DISCUSSION

Choking is preventable. This statement ‘headlines’ the beginning of articles and appears in their conclusions (Berzlanovich et al., 2005; Heimlich, 1977; Kitay & Shafer, 1989), reinforcing the belief if we can just identify all the risk factors for choking and eliminate them, or perform first aid perfectly; choking will no longer be something we need to fear. It will, in theory, no longer be a cause of death for people, with or without swallowing problems. ‘Good’ care will have been achieved and choking as a fatal condition defeated; the human machine ‘fixed’.

The social context of choking represented in this study belies the emphatic nature of such statements or hopes of prevention. Choking, constructed mechanistically, may equate simply with something blocking some part of the airway, restricting or stopping air moving in or out of the lungs. However, why and how something comes to block the airway or how it gets removed is far from simple. Choking is highly complex. Choking events and fatality may be preventable for some but not for others. Care therefore needs to consider both outcomes – prevention and death – so that the breadth of the needs of at-risk adults and their informal and formal carers in the social context of choking can be acknowledged and addressed.

This study sought to explore the social context of choking and its implications for care. It did this using grounded theory methodology with the goal of identifying a theory that would explicate: *‘What kinds of things happen around at-risk adults as they live and die with choking risk?’* Three key conceptual categories emerged from the data that captured ‘what things happen’, ‘why things happen’ and ‘the impact of things happening’ – these categories were awareness, response, and acknowledgement.

The category of awareness was conceptualised as ‘being actively alert or attentive to an area of concern and therefore primed to respond to it’. The category of response was conceptualised as ‘the engagement with a

concern'. The final key category acknowledgement, was conceptualised as 'the recognition and acceptance of concerns'. The data illustrated the various expression of these concepts, showing their complexity and inter-connectedness. Together, they represented an over-arching core category – 'considered support'.

The theory of considered support for choking is conceptualised as 'Thinking carefully about the constellation of concerns and people involved in any particular choking risk situation in order to aid or help those who are potentially at risk of choking and those who care for them'. The theory of considered support does not negate the existing dominant paradigm around choking; that of prevention (reducing risk of choking) and intervention (providing aid if choking occurs). Rather, the preventive and/or interventionist approaches are absorbed into the theory as a part of the possible outcome of considered support. The theory of considered support does however challenge that prevention and intervention should be the sole focus of care when choking is a concern. Quality of life considerations need to be identified and addressed, and care needs to consider not just the at-risk adult, but those others involved who may be affected by choking and thus also need support. The purpose of the theory of considered support is to acknowledge and address the needs of at-risk adults and their informal and formal carers.

What follows is a brief summary of the contribution the social context of choking makes to our understanding of prevention, intervention, and the additional concerns important to at-risk adults and their informal and formal carers.

SECTION 1: THE SOCIAL CONTEXT AND CONSIDERED SUPPORT

Insights into prevention and intervention: Where does considered support fit?

The social context of choking illuminated that at-risk adults and their informal and formal carers may lack certain substantive knowledge and practical skills important to choking and its management. The absence of such knowledge and skills impacted negatively on their awareness and ability to respond proactively to either reduce choking events or manage them when they occurred. Substantive knowledge identified as potentially significant in promoting positive awareness and response incorporated knowledge of dysphagia (identifying signs and management strategies) and knowledge of choking (identifying risk factors and the signs of choking, as well as managing factors and events including the provision of care after an event). Shortfalls in the knowledge and skills necessary to reduce risk and manage choking events in at-risk adults have been identified in the literature (Bennett, Ward, & Scarinci, 2015; Chadwick, Jolliffe, & Goldbart, 2002; Guthrie & Roddam, 2011). As previous studies have proposed, addressing such knowledge deficits may both reduce the risk of choking events and associated harm if they do occur (Cleary & Hopper, 2010; Pelletier, 2004).

Of particular note, this study reinforced the finding of others that basic first aid training may not be sufficient to support at-risk adults because of the challenges that their medical conditions and disabilities may pose to the competent application of techniques (Anderson, Gaetz, & Masse, 2011; Guthrie & Roddam, 2011). It also expanded on these findings by illuminating additional challenges, the acknowledgement of which could inform content for choking first aid training in order to support informal and formal carers (Appendix 5). This study also identified that informal carers may be ill-prepared to respond to choking events such that the outlining of ostensibly

simple responses, for example when to call an ambulance, may achieve better outcomes and carer support. Education and training is an obvious response to knowledge deficits; coroners frequently made training recommendations (targeted at formal carers and assisted-care settings) for increased training in dysphagia and choking management as well as knowledge of general organisational processes.

This study illuminated further dimensions to choking awareness and response that indicated that knowledge alone was not sufficient. These dimensions included ensuring awareness remained current, understanding information and how it connected to other care needs, effectively communicating knowledge, consensus of care goals, and having the practical skills to meet these goals. Exploration of the social context of choking highlighted difficulties with both prevention (identifying and managing risk factors) and intervention (identifying choking events and managing them). Those who needed knowledge did not always have it, despite assumptions by others (managers, colleagues) and perhaps themselves that they both possessed and could act upon it.

The theory of considered support in action would identify: who needed knowledge in a particular context; the nature and extent of knowledge and skills required; the practical application of that knowledge; and support to problem solve around challenges. This part of considered support would resonate with a biomedical model of care and therefore be conceptually familiar. However the theory of considered support would not limit inquiry, analysis of need, or recommendations to that framework; it would actively pursue how choking risk and attempts to manage them were impacting on all involved and in areas that went beyond a consideration of risk.

The theory of considered support would be open to the possibility that at-risk adults and carers may or may not be solely invested in care focused on prevention and intervention. A part of considered support would be checking with both at-risk adults, informal and formal carers, as to what impact choking risk had on them and their 'role in the social context'; what barriers and

supports they felt were present in regard to risk prevention or intervention and ask how focusing on risk reduction and harm minimisation impacted on the at-risk adult's preferences, choices and care relationships in the social context. Considered support would actively focus on the whole picture of which risk reduction and harm minimisation would be only one component. The whole picture illuminated in the social context of choking would include looking beyond prevention of risk and harm to recognise quality of life considerations and how living with the risk of choking might give rise to planning for end of life, given the reality that not all choking risks can be controlled.

Insights beyond the focus on prevention: Where does considered support fit?

Considerations not focused on risk

The social context of choking illuminated that risk and its reduction was not a concern for some at-risk adults or their carers. Awareness of risk was either not possible because there were no signs leading up to a fatal choking event, or because cognitive or knowledge deficits rendered recognition of risk difficult. Risk and its reduction when awareness was present was not the only concern of at-risk adults and their carers. For some, quality of life considerations as expressed in preferences, choices or formal decisions to refuse treatment recommendations, over-rode a desire or commitment to eliminate all possible risk factors.

A number of the strategies used to try and prevent choking came with burdens. In the social context of choking three particular strategies were identified in the study sample as having a stated negative impact on how some at-risk adults wished to live their lives; these strategies were being fed by others, supervised by others, and the use of texture modified food, and the negative associated with all these appeared to be predominantly related to loss of pleasure and independence. The major risk-reducing strategy refused by at-risk adults, with or without decisional capacity, was TMF. It was

apparent from the findings however that a rejection of this strategy did not equate to a rejection of all risk-reducing options by most at-risk adults.

While TMDs created burdens for some at-risk adults, the rejection or refusal of them also created burdens for some informal and formal carers. In assisted-care settings these burdens included navigating ethical and duty of care issues, and trying to balance QoL considerations with a risk-reduction imperative. Additionally, for both formal and informal carers, refusal of treatment strategies potentially increased anxiety around feeding high-risk foods to at-risk adults and the need to respond to a potential choking event.

Some assisted-care settings enforced TM diets despite those consuming them reporting their dislike, while others supported individuals' preferences and QoL decisions; such support often involved compromises where some non-TMF was provided or a TMD that was less restrictive than that recommended was given. There was evidence that how and how well preferences and QoL decisions were managed could depend on setting, creating inequalities in how care for those at risk of choking was provided. Those at-risk adults living at home had maximum power to make preference choices. No coronial censure was apparent when informal carers supported preferences that went against risk reduction. However there was evidence of censure when staff in assisted-care settings failed to provide the recommended TMF. Findings however also indicated that coroners did not negatively judge care that supported QoL preferences over risk reduction in assisted-care settings, as long as other risk factors were managed and there was evidence of well thought out care plans, formal decision making processes, and involvement of appropriate carers (both informal and formal). When these conditions were met, no coronial censure was evident. Thus in the social context of choking, not only was there a need to reduce risk but also to find a balance between risk and QoL considerations in order to respect individual preferences and determinations of best interest. From the perspective of some coroners at least, such balance was a part of good care, as long as there was formal evidence that risk had been identified, considered and reduced as much as possible.

As noted in Chapter 2, this balancing act between risk and quality of life in regard to choking is not necessarily a comfortable space, with intense debate occurring about duty of care, autonomy and the consequences of refusal of treatment to both the at-risk adult and others involved; a part of this discussion also includes the acceptability of carers withdrawing from the care relationship if they feel compromised by an at-risk adult's refusal to follow recommendations (Sharp & Bryant, 2003; Wagemans et al., 2017). The findings in this study reinforce that at-risk adults *do* refuse TMF and also seems to reinforce that the most feared consequence of *allowing* them to do so is death.

The value of exploring choking from a social perspective lies in its providing depth and breadth far beyond the biomechanics of choking and associated issues. At-risk adults who refused TMF died in this study, as did at-risk adults who did not refuse TMF. Did individuals die because of what they were eating or because of the multiple other risk factors present at the time: did they die because of risk factors or because first aid was not competently applied; did they die because first aid was competently applied but the texture of the food made it impossible to dislodge; did they die because first aid is not currently technically adequate for all choking scenarios; did they die because there was no one there to provide aid or the person who was there had their own disabilities? The answer to all of these questions is 'yes' within the total study sample, highlighting the multidimensional nature of the phenomenon that is choking. More research is needed on the social context of choking, at least in part because this study sample is skewed; indeed everyone at risk of choking choked and died. But their deaths and their uniqueness and commonalities show how much we do not know. The findings provide an important perspective for both ethical and clinical arenas, that being the reminder that likely no one recommendation, accepted or refused, can currently guarantee either life or death in regard to choking. In light of this, perhaps those being prescribed TMDs can do so in a more informed fashion, while carers can sit more easily with the discomfort of

staying involved and supporting the at-risk adult in reducing those risks that do not create unacceptable burdens for them.

In light of the dual considerations of how important food can be to people and what we do and do not know about choking and its relationship to TMF, the theory of considered support would acknowledge multiple conceptualisations (informed by the social context) such as:

Certain foods may be a risk factor for choking, and therefore the ability to offer – based on an assessment of an at-risk adult's swallowing problem – alternative food consistency options is an important part of care; and

Certain texture modified diets may create such burden for some at-risk adults as to make their use as a management strategy to reduce choking risk inappropriate.

In the theory of considered support, such different conceptualisations would prompt the need for different support for carers and at-risk adults. Such support could include knowledge, advocacy, decision-making and other processes, as well as psycho-social-spiritual aspects, all as determined by the context.

Acknowledging death and the need for support

The social context of choking illuminated that despite attempts to reduce risk and the presence of skilled first aid and advanced medical interventions, at-risk adults still died of choking. Acknowledgement of the limits to prevention and intervention and the possibility of brain damage or death as a consequence of choking is important. Recognising such limits may stimulate more research on the identification and control of risk factors and the development of new aid techniques into the future. However, based on this study's findings from exploring choking within the broader social context in which such events take place, there is an opportunity to also focus on the needs of those who currently live with the possibility of the consequences of choking and who may need or wish to be prepared for it. One of the challenges of approaching care in regard to choking is how it is perceived. Anyone can choke, and people do so without any underlying medical

condition and in most cases due to an externally introduced precipitator (Haugen, 1963). Choking is therefore commonly perceived as a non-natural event and cause of death; unexpected and accidental. However for some of the at-risk adults encountered in this study, this perception is challenged.

In discussing do not resuscitate orders for people with intellectual disability, Wagemans and colleagues state: “it is becoming increasingly clear that choking is inextricably linked to dysphagia problems in many people with intellectual disabilities, and is part of the specific epidemiology” (Wagemans et al., 2017, p. 252). This view was reinforced by the comments of some forensic pathologists encountered in this study, who when confronted with particular diseases suggested that choking was not an unexpected consequence. Whether this linking of choking with particular diseases is as clear-cut as it seems, or illustrates that the social and cognitive factors which accompany certain conditions generate a matrix of multiple risk factors for choking, is unclear. What is suggested however is that in the presence of dysphagia, recurrent choking events or particular conditions such as intellectual disability, choking becomes a likely cause of brain damage or death. As such, decisions may need to be made in regard to end of life quite explicitly. In this study there was evidence that at-risk adults and/or their surrogate decision makers had considered end of life care and indicated decisions as to what form it should take, although these decisions appeared to be general rather than choking-specific. When such decisions had not been previously made but became necessary, informal carers had to make such decisions. Some decisions were enacted at the scene of choking and others in the hospital setting. There was some evidence that while choking had similar outcomes to other catastrophic events, it may or may not be considered as separate from end of life care and decisions, but the possibility at least ought to be acknowledged.

A part of considered support therefore would be to anticipate the possible need for at-risk adults and surrogate decision makers, if they wished, to include choking in their end of life plans and decision making. Considered support would provide a space to reflect on the different levels of intervention

possible and what seemed most appropriate given the at-risk adult's views and social context. In considered support, this discussion space would not only be focused on the at-risk adult's wishes but would also consider the possible impact of any decisions on informal and formal carers, and whether in supporting different decisions certain caveats would need to be in place, such as family wanting to attempt CPR if a choking event occurred in the home, but a DNR order in place if the at-risk adult was in an assisted-care setting or receiving palliative care. The purpose of such support would be to provide clarity in regard to the goal of care for all those involved, taking into account environmental, duty of care and emotional considerations with respect to decisions and possible responses.

Considered support would also create the opportunity to reflect on what could or should happen in the space between obstruction and death. The need to ensure basic intervention – which could remove the obstruction with no adverse effects – is not ceased too soon, balanced with accepting death with all possible comfort provided, and all the other multiple happenings that could take place in this space. As illuminated in the social context of choking, that time between obstruction and death can vary in length and complexity, however the identification of at-risk adults at least makes it possible to be prepared to provide the best care possible.

The different aspects of considered support would require a team approach; a team that is both inclusive of those immediately concerned but also functions to provide care by sourcing different levels of knowledge and expertise when necessary. The theory of considered support has an affinity with a number of different health care approaches which could inform a team attempting to navigate the challenges of choking.

SECTION 2: THE THEORY OF CONSIDERED SUPPORT AND ITS AFFINITY WITH DIFFERENT APPROACHES TO CARE

A primary feature of the theory of considered support is the acknowledgement of and necessity to address the needs of the at-risk adult, and their informal and/or formal carers. Consideration of these three seemingly disparate groups with likely distinct needs with respect to the issue of choking and choking risk seems particularly challenging. However there are three existing approaches to care that may substantially inform the theory of considered support, adding conceptual depth and practical guidance as to how it might work in practice. The three approaches which resonate with the theory proposed in this study are person-centred care, family-centred care, and relationship-centred care. These three approaches of care will be briefly reflected on in relation to how they might assist in promoting and providing considered support in choking care.

Person-centred care; considering the at-risk adult

In clinical practice there has been an increasing imperative to provide a patient-centred – now being reframed as a person-centred (Australian College of Nursing, 2014) – approach to health care, with mandatory training part of employment in some health departments. Person- or patient-centred care is still an evolving philosophy and paradigm with no definitive definition, but it has gained traction over the past 25 years as a successor to the biomedical model (Mezzich et al., 2010; The Health Care Foundation, 2014). It is supported by the World Health Organization, Australian and US governments, care organisations and consumer groups (Kitson, Marshall, Bassett, & Zeitz, 2013), and expands the biomedical model to incorporate a biopsychosocial framework, where the consideration of the individual's perception of wellbeing and involvement in decision making is an important part of positive health care outcomes (Mezzich et al., 2010). Its meaning and

practical application however can prove elusive, as different organisations and health care disciplines attempt to apply the rhetoric of person-centredness to daily practice (Anderson, 1995; Mezzich et al., 2010).

Investigating what constitutes the core elements of patient-centred care, Kitson and colleagues reviewed 60 papers (1990-2010) from health policy, nursing and medicine in the acute care sector to identify the core elements of this approach. Focusing particularly on the seminal work of five research teams in this area, Kitson's team identified three themes underpinning patient-centred care: patient participation and involvement; the relationship between the patient and health care professional; and the context in which care was delivered. Elements contributing to these themes included: respect for patient values and preferences; involvement of family and friends; education and communication; clinical decision making guided by the individual; and sharing of power and responsibility (Kitson et al., 2013).

Person-centred care therefore lends itself to a broader view of wellbeing and health that incorporates the at-risk adult's unique personal story and their perception of quality of life based on values and beliefs within the experience of illness. The person-centred care paradigm does not preclude risk reduction or death prevention. The Australian College of Nursing in its 2014 position statement on person-centre care, presented evidence that such a philosophical approach to nursing improved health outcomes, specifically including reducing heart attack mortality and hospital acquired infections (Australian College of Nursing, 2014).

As an approach, person-centred care would seem, with its focus on the individual and what is important to them in their context (Kitson et al., 2013), to capture the concerns of at-risk adults identified in this study and provide a mechanism to have their needs met. Person-centred care would temper the theory of prevention at all costs and address QoL considerations and potentially explore end of life wishes; it would also hopefully trigger the need for appropriate health professional assessment and reviews. Some of the stories in this study appeared to reflect a person-centred approach. However

while person-centred care acknowledges the involvement of family and friends (Kitson et al., 2013), care remains focused on the individual, in this case the at-risk adult.

However, when working with such a strong paradigm as prevention and its imperative to preserve life, it can be difficult not to view person-centred care as synonymous with reduction of risk. This may be particularly so when, because of communication and cognitive problems, at-risk adults may not be able to self-advocate for a broader approach, other than through behaviours such as resisting certain foods and seeking out others. Such behaviours or indeed well-verbalised refusals in conflict with recommendations and goals made to reduce risk, may be inappropriately attributed to non-compliance due to an assumption of individual inability to understand risk. Certainly this may be a part of what is happening, however at-risk adults with decisional capacity do refuse some recommendations, while others choose to control all risk. While often associated with QoL and situated in that debate, there is a further argument for why people may be willing to take risk and why it should be supported. This argument is based on the theory that being able to take risks is part of being fully human and in that sense confers or reinforces individual dignity.

The dignity of risk

‘The dignity of risk’ as a concept was first proposed by Robert Perske in the 1970s. Perske studied the growing interest in Scandinavian countries in developing a model of care for those with an intellectual disability⁵⁰, which included experiencing risk taking as a part of the experience of healthy living (Perske, 1972). Perske believed there was “...a dehumanizing indignity in safety” (Perske, 1972, p. 29). Other authors have taken Perske’s term and its conceptualisation, applying it to other populations such as those living with mental illness and the elderly; reinforcing its desirability but acknowledging

⁵⁰ At the time Robert Perske was writing, people living with an intellectual disability were referred to as mentally retarded, this label has since been replaced to better respect the dignity of those with cognitive difficulties. In 2007, after 50 years the journal publishing Perske’s work changed its name from *Mental Retardation* to *Intellectual and Developmental Disabilities*, reflecting the dignity it showcased (Society for Accessible Travel and Hospitality, 2007).

both barriers and its expression being in its infancy (Ibrahim & Davis, 2013; Parsons, 2008). Debjani Mukherjee, while not writing on the social context of choking, nevertheless captures relevant aspects of risk and the narrowness of the clinical context:

The concept of risk itself is one that requires contextualization, assessment, and judgement and can be objective or subjective. Health care providers are often acutely aware of medical risks and have only a small clinical window into the complexities of a patient's life (Mukherjee, 2015, p. 7).

Nay proposes that allowing for some risk is a part of duty of care in health from within a nursing context (Nay, 2002). Person-centred care and the dignity of risk may be intimately connected in choking care. Mukherjee concludes a discussion of the topic in her paper with:

The dignity of risk is a concept that we must keep in the forefront of our practice; the risks, after all are our patients' to take (Mukherjee, 2015, p. 8).

While this may be so, some of the risks at-risk adults take impact on and create risks for others. Hence person-centred care does not provide sufficient guidance or support to meet all the demands and challenges of the social context of choking.

A focus on the needs of an at-risk adult would nevertheless seem essential. However an exploration of the social context of choking showed that the domains of 'risk' and the need for support were not only relevant to the person who may choke but also to their carers. Person-centred care as it is currently conceptualised is not sufficient to address the needs of informal carers who, like the at-risk adult, may be intimately involved with the challenges of choking and the limitations prevention and intervention present. An approach to care that includes empathy toward the specific needs of informal carers is family-centred care, as represented by the palliative care model.

Family-centred care; considering informal carers

Family centred care considers the needs of informal carers. Palliative Care Australia (the peak body for palliative care in this country) asserts its commitment to family-centred care, in alignment with the World Health Organization's directive that palliative care as a model of care supports both the person with the life-threatening illness and their families; offering a support system to assist families or friends in their care-giving and to provide bereavement support after death (Palliative Care Australia, 2017; World Health Organization, 2017). Practical, educational, psychosocial and spiritual support is offered, in acknowledgement of the complex needs of the informal carer. The palliative care model has much to offer choking care and the theory of considered support. Choking is potentially a life-limiting consequence of dysphagia and other associated factors placing the person at risk. Many of the concerns that arose in the social context of choking resonated with the situations and issues faced by people and their families dealing with life-threatening illnesses, such as the tension between prolonging life through risk reduction or advanced medical interventions versus quality of life considerations during and at the end of life. Therefore it is imperative that any approach to care considers them in their own right.

In this study, informal carers, family members or friends were often intimately involved with choking risk and/or choking events and their aftermath. They may have had no or limited knowledge of choking and/or its risk factors and been caught by surprise when a choking event occurred, or they may have been a part of trying to control risk factors or promote QoL considerations through the preparing and giving of particular foods and promoting other recommended strategies. Regardless of the level of awareness and involvement before a choking event, if a choking event occurs family or friends will literally, by their very presence, be in a position to respond. A little or a great deal may be expected of them by the person they are caring for, health professionals and/or themselves.

In the social context of choking there may be no opportunity to provide individuals or family with support, educational or otherwise, because choking risk may not have been identified. However based on the findings of this study, for those carers whose family members have been identified with multiple risk factors for choking or are experiencing choking events, a family-centred approach to care would help address their needs. Even if the at-risk adult is not at particular or imminent risk, family members may be anxious about choking, reinforcing the value of incorporating relevant content into support measures. For informal carers, providing – if necessary and wanted – an opportunity for them to have their individual personhood and needs acknowledged would be a part of considered support.

Relationship-centred care; considering all

Many formal carers are involved in the social context of choking. These carers have different roles, different levels of knowledge, and different levels of responsibility. While those with professional backgrounds such as medicine, speech pathology or nursing may have the greater knowledge and therefore perceived greater responsibility, directives from such professionals are often fulfilled by carers such as personal care assistants, who have the least knowledge but the most ongoing relationship with the at-risk adult. These carers providing day to day care may also have to immediately respond if a choking event occurs. In the presence of known choking risk, whatever recommendations health professionals make, whatever decisions or choices an at-risk adult or their surrogate decision maker makes, and whatever actions direct carers take, everyone in the social context of choking is connected by a web of relationships and roles. Whatever happens positively or negatively can impact on everyone. In the web of relationships which is inherent in the social context of choking those involved may have competing concerns.

In the 1990s growing dissatisfaction, of both health practitioners and patients, in the delivery of health services in America spearheaded debate on the need for a new philosophical approach to health care and the interaction between

health practitioners and patients. The Pew Health Professions Commission was set up to analyse the past and present health care system and provide a vision for the future (Beach & Inui, 2006). From this analysis, two evolutionary approaches were considered to be at play; the doctor-centred approach, where the provision of care was based on the preferences and values of the doctor, and the patient-centred approach, where the preferences and values of the patient were the focus (Beach & Inui, 2006). The Commission set up a Task Force to analyse and consider these two approaches, drawing on the evidence and practitioner and patient preferences of both, and advance a third approach "...based upon the interdependence of psychological, social and biological factors" (Beach & Inui, 2006; Nolan, Davies, Brown, Keady, & Nolan, 2004, p. 48). The Task Force's envisioned new approach was named relationship-centred care (RCC).

Relationship-centred care was proposed to address the philosophy that:

Relationships provide the context for many important functions and activities in health care. Within relationships, we exchange information, allocate resources, arrive at diagnoses, choose treatments, and assess the outcomes of care. None of these is carried out solely by 1 party; all are mediated by the qualities of manifold relationships that link patient, clinician, team, organisations, and community (Beach & Inui, 2006).

While the original rhetoric of relationship-centred care focused on the doctor and patient relationship, coming as it did from a desire to move beyond the silo-creating historical doctor-centred care versus patient-centred care approaches, the concept can be applied more broadly. Nolan and colleagues explore it from a nursing perspective and its value, particularly in aged care (Nolan et al., 2004).

The dimensions of relationship-centred care identified by Beach and colleagues (who focus on the doctor as clinician) are: the clinician-patient relationship; the clinician-clinician relationship; the practitioner-community relationship; and the clinician relationship with self (Beach & Inui, 2006, p. S6). These dimensions, relabelled with *formal carer* rather than clinician

(though inclusive of doctors) and at-risk adult in the choking context, could provide a framework and guidance for elucidating the multiple relationships potentially at play in the social context of choking and the promotion of considered support. The following teases out some of these relationships in the choking context.

Formal carer/At-risk adult relationship

The formal carer/at-risk adult relationship would be recognised as a:

...unique product of its participants and its context. In RCC, the quality of communication between...[*at-risk adults and formal carers*]...is not viewed as a result or outcome of 1 single party, but as an interactive process that is dependent on the efforts of both participants (Beach & Inui, 2006, p. S6).

Such a perspective would acknowledge that engagement with concerns would require mutual knowledge, and mutual communication including the at-risk adult as much as possible, while also acknowledging that a surrogate decision maker may also be required.

Formal carer/Formal carer relationship

Beach and team propose that:

The energy and enthusiasm that a practitioner brings into the consultation with a patient is profoundly influenced by the practice and larger organization's values and integrity. Relationship-centered care emphasizes that clinicians ought to listen, respect colleagues, appreciate the contributions that colleagues from other disciplines bring, promote sincere teamwork, bridge differences, and learn from and celebrate the accomplishments of their colleagues (Beach & Inui, 2006, p. S6).

By adhering to the values and practices outlined above, the well-being of all is enhanced. In the theory of considered support such a relationship between formal carers would need to acknowledge the hierarchy of carers involved in providing care to adults who are at risk of choking. Those providing care can include catering staff, personal carers, nurses, allied health professionals, facility managers and doctors. Often those at the least skilled level are the

ones who spend the most time with at-risk adults and provide the daily direct care (Wagemans et al., 2017). Efforts therefore would need to be made in acknowledging and overcoming the typical imbalances in influence that occur when those involved in care are so varied.

Formal carer/Community relationship

As illustrated in this study, at-risk adults connected with and were a part of many different communities or care settings:

Because the root causes or determinants of health are multiple (biologic, environmental, social, psychological, behavioral, economic, and medical care-related), the clinician and clinical team will need to 'reach into' many sectors, form meaningful relationships with others, and sustain these 'therapeutic partnerships' if effective care ...is to be possible (Beach & Inui, 2006, p. S6).

Formal carers in the social context of choking may work across different settings and encounter different communities, such as personal carers providing care in the private home context versus in an aged care facility, or speech pathologists providing consultative services in various settings. Different care organisations will vary in resources and sophistication of understanding around the challenges of the social context of choking. Knowledge of choking and all its ramifications is not easy to come by, making it difficult to provide support. In this regard, particular formal carers may in the future need to take a lead or facilitating role, providing a resource that can be accessed across different settings. The suggestion that speech pathologists may be appropriate for this role will be discussed in Section 3. The theory of considered support would acknowledge and require an understanding of different 'communities'; their structures and beliefs around care, their perceived or real vulnerabilities around supporting QoL versus prevention, and their resource limitations. Part of this understanding would acknowledge the social context of choking as part of the larger community of health care, which can include general community values, formal standards such as accreditation programs, and the coroner's office, and how communication between all these diverse, micro, meso, and macro communities interact.

Formal carer relationship with self

In regard to providing a vision of the future of health care, the Pew-Fetzer Task Force proposed that: “The biggest ‘psychosocial’ problem facing us may be the need for our own personal transformation – to understand and promote change within ourselves” (Beach & Inui, 2006, p. S7). This final dimension of relationship-centred care was defined as: “...the individual's capacity for self-awareness, depth of self-knowledge, and capacity to create and sustain personal integration (‘wholeness’ or integrity) in complex and challenging circumstances” (Beach & Inui, 2006, p. S6). Choking is complex and challenging. It may seem inappropriate to apply the dimensions and ideals of relationship-centred care on all formal carers, not those just deemed as ‘professionals’. However, regardless of how our society recognises and values care roles, choking demands considerable degrees of responsibility and response from all carers, including knowledge, skills and the ability to address and come to terms with the ambiguities and challenges around choking and related care. Considered support would acknowledge that many of the aspects of choking can ethically and personally challenge formal carers, requiring a need for resilience and ‘wholeness’. Considered support would acknowledge that health care professionals often have supports in place as part of their professional structures and standards that other formal carers – in the social context of dealing daily with the possibility of having to manage choking and death – do not.

Relationship-centred care perhaps best represents the breadth of interconnections which are a part of the social context of choking. However in a web of relationships, if there is conflict, which relationship is the most important to preserve? Person-centred care would suggest that focusing on the at-risk adult's relationship with self, and what that might mean, regardless of their decisional capacity, may need to be the starting and end point of care in viewing all relationships within the social context. Considered support however would attempt to ensure that such a view did not sacrifice the care of others and their personhood in the process, providing them with support to meet the challenges that they may individually face.

SECTION 3: THE BLOCKAGE IN THE MACHINE: WHERE CONSIDERED SUPPORT SITS

None of the theories outlined above address all the aspects required of the theory of considered support in the social context of choking. Together however, they do embrace a view that in complex care situations, every person involved and every relationship may enhance or diminish each person's wellbeing. The social context of choking illustrates that there are multiple demands present for all involved with choking risk and choking fatality. It is a complex area of care. In the social context of choking everyone is linked; considered support of one will logically flow to the consideration of others, as connected concerns are acknowledged and addressed. Thus helping and supporting one individual or group may help and support others.

Choking as a condition appeared to perfectly fit and reinforce the biomedical model. At the time when its care was first being formulated, the goal was to understand the mechanics of choking and remove a blockage when it occurred. When that proved challenging the focus split, and making sure something did not block the machine in the first place was added to the conceptualisation of care.

The theory of considered support is a new conceptualisation of how choking could be viewed. In grappling with the social context of choking and its implications for care, the theory of considered support has to acknowledge the value of all and consider that what is of concern to one is a shared – though at times a perhaps unwelcome and/or unrecognised – concern for all. As such, an equilibrium has to be found that: speaks to general anxieties; addresses risk and quality of life and the possible tension if these two dimensions are at odds; gives prevention and acceptance of death equal attention; and recognises the limitations of current thought and what can be claimed about choking risk and its control. Choking, an early poster child/condition for the biomedical model of care, has shifted to becoming a possible promoter of a more social model of care.

Possible implications for speech pathology

Choking as a topic of care relevant to at-risk adults impacts on and involves many people. Like any complex health issue, a team approach to clinical care is required to address related concerns. The theory of considered support expands the demands usually associated with choking, requiring those involved in care (the team, including the at-risk adult and their family) to balance a consideration of prevention and intervention with the broader concerns and challenges of choking, while also considering the impact on all. In reflecting on the social context of choking and its complexity, the question arises as to who in the health care system is well placed to consider all aspects of choking for at-risk adults as a phenomenon and address its impact on those faced with its challenges? Who could act as a resource and facilitator to understanding its complexity? Speech pathologists may be well situated to consider taking this role.

This research arose out of a desire to understand more about an area that speech pathologists, by nature of their leadership in dysphagia care, are already engaged in. The at-risk adults whose stories were explored in this study by definition were or could have been linked to speech pathology services. That many did not appear to have access to such services is a concern in itself. However even if that concern were addressed, the social context of choking poses challenges to speech pathology engagement. As discussed in the literature review, speech pathologists by nature of their history and training are heavily invested in the prevention paradigm; they are also committed as part of their professionalism to the concept of person-centred care. Choking can create tension between these two objectives. These tensions are compounded by what is not known about choking; whether strategies such as TMDs which may assist with some aspects of dysphagia care (increasing swallowing comfort and helping reduce aspiration) may actually be contra-indicated when viewing choking management as an entity in itself. Thus in light of current knowledge, dysphagia and choking may need to be seen as two intimately connected issues but requiring different approaches that require a balancing of different

risks and benefits. In addition to this possible shift in perspective would be a redefining of care to incorporate the importance of social context, including supporting QoL considerations despite the potential for fatality, and as appropriate assisting at-risk adults and their informal carers to understand the place of choking in advance care planning.

A clinical approach to a medical problem such as difficulty swallowing can be perceived through the lens of four care approaches: preventative, restorative (or rehabilitative), supportive, or palliative, with some potential for overlap (Chahda, Mathisen, & Carey, 2017). Chahda and colleagues have suggested that speech pathology engagement in palliative care, while having much to offer, can be challenging as the profession is routinely engaged in prevention and rehabilitation goals and their associated activities, which may be in conflict with more supportive and palliative goals and activities (Chahda et al., 2017, p. 59). These authors see palliative care as an advanced health care practice, and speech pathologists working in this area as requiring a “person-centred approach to intervention, an understanding that bioethical principles such as patient autonomy (‘freedom of choice’) may not always correlate with the therapist’s goal of beneficence (‘to do good’) thus SLP⁵¹-related issues may not take precedence” (Chahda et al., 2017, p. 63). A re-conceptualisation of choking within the theory of considered support would still resonate with the traditional functions of the speech pathologist’s role of prevention and rehabilitation, but would challenge speech pathologists to expand their practice to include support and palliative care goals and activities. Speech pathologists working in palliative care may be well placed to consider choking, under their expanded and advanced view of practice, as a life limiting condition requiring the capacity to move across all four clinical approaches depending on the social context.

The theory of considered support is practically ambitious, however preliminary knowledge gained from the exploration of the social context of choking and the identification of both the key categories and the core

⁵¹ SLP – speech language pathologist.

category of considered support have already informed practice. The following is a description of a choking management service that was developed to address some of the primary needs of at-risk adults and their informal and formal carers, informed by the provisional findings of this study of the social context of choking

Application of the theory of considered support in clinical practice

PhD research and thesis writing by its nature is a long process and the application of findings often belongs to the future. However as a researcher with a training and consultancy role and in partnership with colleagues (speech pathologists involved in direct client care) it has been possible to apply some of the findings of this study (increased substantive knowledge and insights) to reinforce and expand how we perceive and provide care for at-risk adults and their informal and formal carers in our public health service. As an adjunct to our clinical service and informed by some of the findings of this work, we have developed a choking management service which is education- and support-based. This service has been established to practically address clinical, ethical and/or psychosocial issues that arise for at-risk adults, informal and formal carers, care organisations and speech pathologists as part of the social context of choking.

In brief, the service offers training, advice and support.

The training component offers 3 types of practical choking management sessions which range from 1.5hrs – 2.5hrs.

These sessions have a practical component and a knowledge/psychosocial component

- The practical component includes: first aid choking training; challenges encountered doing first aid on people with physical and/or cognitive problems; challenges encountered by carers (because of their size, strength etc.); and the problem solving of such challenges.

- The knowledge/psychosocial component includes: discussing fears around choking; myth busting around choking; managing QoL decisions that may sit in tension with risk reduction; the relationship of choking and resuscitation; advance care planning; what happens if someone dies of choking (coronial investigations); and debriefing on choking events. This content is available for discussion in all sessions but is determined by the needs of those requesting the education/support.

We proffer one session for clients (at-risk adult) and their family members/friends (usually at their home) on request; referral to the service is via the client's speech pathologist who attends the session. The clinician, who has already established a relationship with the client and their family and offered advice and recommendations on risk reduction, attends the session to both provide emotional support in acknowledgement that it is a potentially confronting topic for clients and informal carers alike, and assistance around any decision making regarding risk-reduction and QoL considerations. Speech pathologists outside our health service can also refer clients and their informal carers.

Triggers for referral include the speech pathologist, client and/or their family concern or anxiety about choking – this can be from a concern related to possible risk or the client experiencing choking events. As clients in the community, often for quality of life reasons, decide not to follow all risk-reducing recommendations, this session has the advantage of reassuring clients, their family/friends and clinicians that aid can be provided if a choking event occurs.

We also offer sessions for formal carers providing care (in the home or assisted-care setting) for a specific person (with their permission), and one more generic session for formal carers who may provide services to a range of at-risk adults.

In addition to the training sessions we offer a consultative service which formal carers can access for support and problem solving. As a consequence of a high uptake and positive feedback from at-risk adults, informal, formal carers and assisted-care organisations, we are developing in-house advance practice competencies to develop a skill base in the speech pathology department so that the service can continue in to the future.

Limitations of the study

A notable limitation of this study was the use of secondary data. The data were not originally collected to study the social context of choking, nor was it collected by the researcher: "Primary data originates from a study in which a researcher collects information him/herself to answer a particular research question" (Andrews, Higgins, Andrews, & Lalor, 2012, p. 12). In the case of coroner's reports (the data used in this study), the initial researcher (the coroner) studying an individual's death collected (via his or her research assistants: police, forensic pathologists, toxicologists) information to answer the questions of who died, what was the cause of death and what were the circumstances surrounding the death. While the use of secondary data has multiple advantages (for this study access to an otherwise hard to reach sample and sensitive topic) it also has limitations.

An overall issue was limited or missing data; some reports were only a few lines long with limited medical history or no circumstances recorded (the circumstances of a death, prehistory and what took place when someone choked was the source of much of the social information needed for this study). It was also of possible significance that the NCIS data base from which the data was drawn only had the formal reports of investigations, and not additional police and coroners 'notes' (field notes and memos of the original investigators), which determined why some cases were comprehensively investigated and documented and others at least superficially appearing similar (for example 'person with dementia choked at meal in aged care facility') were seemingly not.

Connected to the above issue of 'missing' data in regard to the aim of this study is the possibility of skewed data, not only related to the primary purpose of why the data were originally collected but also the conditions under which much of the original data were gathered. The stress of being involved in a death and the subsequent police investigation is part of the social context of choking. The timing of data collection and the method of questioning is however likely to have influenced the accuracy of first hand descriptions of events. Whether this was a favourable or unfavourable influence is unknown. Certainly discrepancies were noted by coroners between reporting of events at the time and many months later at inquests.

The use of a secondary data source also limited the full expression of the grounded theory methodology employed to illuminate the social context of choking in this study. Most significant was the impact on theoretical sampling and theoretical saturation. As described in Chapter 3, theoretical sampling as part of grounded theory is the opportunity to collect data as analysis progresses and return to the original data source in order to develop theory and address gaps or possible deficits (as indicated above) that might be a part of the initial data collection process. When dealing with a secondary data source this is not possible; the avenue however remains open to seek out potentially new sources of data to supplement what you already have. As discussed in the methodology section, unfortunately due to the circuitous route this research took, the volume of data being analysed, and resource limitations this was not possible and is a limitation, however how this might be addressed will be discussed in the future research section.

The use of secondary data is also potentially a limitation to theoretical saturation not only due to the theoretical sampling limitations discussed above but also because a secondary data source may be inadequate to meet a large enough sample to meet saturation, and the subsequent goal of a substantial theory. I believe the sample size and its richness was sufficient both to reach saturation of ideas using the particular data source chosen and to generate a substantive theory. However having said that, the limitation of theoretical sampling if it could be addressed, would add considerably more

substantive information that could be used inform the practical application of this study's theory.

I think it is also of note that the data in this study were also 'secondary' data in that I had analysed the data previously for a quite different reason. While re-analysing data from "...a new perspective with a view to gaining new insights" is not uncommon (Andrews et al., 2012, p. 13), as an inexperienced researcher this may have influenced my interpretation.

Future research

This study provided an overview of the social context of choking as represented in coronial reports. It is hoped that it will stimulate future interest in a broader view of choking and the implications of that for care. In keeping with this hope there are three key areas that would seem particularly worthy of future study.

Pursuing more social data

The first key area would be to pursue research into the broad social context of choking, particularly addressing the limitations of this study which only drew on one source of data, coronial reports. Future research could further explore the concerns identified in this study through direct engagement with those living with choking risk, namely at-risk adults and their informal and formal carers. Such research would not only expand understanding of the concerns identified but potentially identify additional concerns which many not have been represented in coronial reports. Direct engagement with those involved in choking would also illuminate and clarify what they might find supportive in dealing with the challenges of choking. While this study looked at choking as an overarching topic for at-risk adults and their carers, future research with a social focus could also build on work already being done on choking within particular groups of at-risk adults.

Assumed risk versus actual risk

The second key area for study would be the exploration of the concept of perceived or assumed risk and actual risk of choking and choking fatality in at-risk adults. Macciocchi and Stringer (2001) draw attention to the ethical implications of assuming risk, identifying that studies show that clinical predictions of risk are likely to over-stress risk and are less reliable than statistical predictions (Macciocchi & Stringer, 2001). Actuarial studies looking at choking and taking into account the multiple factors implicated in risk and choking fatality would add considerably to the understanding of choking.

Choking and speech pathology

The third key area worthy of future study would be exploring choking as an entity related to but separate from dysphagia and the role of speech pathology in providing care that would encompass its social context. Research in this area could go in various directions, such as looking at how choking is conceptualised in the speech pathology literature. In exploring the topic of choking in the professional literature it was often difficult to determine whether choking was being considered as a type of aspiration or as a separate condition. If the former, in light of the complexity of choking its separation in the literature would be helpful and provide a more meaningful position from which to evaluate compensatory strategies. Another direction would be the study of how speech pathologists perceive choking and its relationship to person-centred care. Additionally choking could be explored as a possible area of advanced practice in speech pathology with a possible alignment with the role of speech pathology in palliative care (Kelly et al., 2016).

Conclusion

Whatever the future research, based on the findings in this study choking is a complex issue that both impacts on and is impacted by the social context in which at-risk adults and their informal and formal carers are a part. At the very least, consideration needs to be given to the confronting nature of the

topic and the often distressing reactions both the risk or its manifestation creates for at risk adults, their families and friends, and all those providing formal care. The fear often present around choking is likely to encourage the belief that prevention and intervention is the only response when contemplating care. It is doubtful that fear as a natural response to choking has in any way been dissipated by this study and its theory. However the choking narrative has illuminated that women and men are far from being machines – where blockages in the airway can be easily prevented or unclogged. The individual stories on which this study was founded showed people living with the risk and manifestation of choking with great courage. The courage to do what they were told to prevent it, the courage to refuse to do what they were told and take a risk, the courage to respond – well or not so well – but to be there in the moment with choking and with death. The courage to make difficult decisions, pre-planned or unprepared. The courage to be humans not machines. Author James Stephens wrote “curiosity will conquer fear even more than bravery will” (Stephens, 1918, p. 13); in 250 years of studying the topic, there remain things unknown and unresolved; the social context of choking provides more opportunities for curiosity alongside the bravery of at-risk adults and their informal and formal carers.

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Appendices

Appendix 1

**A snapshot of factors thought to predispose
adults to choking**

Appendix 1

A snapshot of factors thought to predispose adults to choking

Please note: This is not an exhaustive list of either risk factors or authors who have suggested risk factors.

Person related - Physical

Medical diagnosis – general

- Neurological conditions
(Berzlanovich, Fazeny-Dörner, Waldhoer, Fasching, & Keil, 2005; Cleary & Hopper, 2010; Soroudi et al., 2007; Wick, Gilbert, & Byard, 2005)
- Mental illness
(Aldridge & Taylor, 2012; Fioritti, Giaccotto, & Melega, 1997; Guthrie & Roddam, 2011; Wick et al., 2005)
- Concurrent neurological disorders
(Aldridge & Taylor, 2012)

Medical diagnosis - specific

- Alzheimer's/Dementia
(Berzlanovich et al., 2005; Cleary & Hopper, 2010; Dolkas, Stanley, Smith, & Vilke, 2007; Soroudi et al., 2007)
- Learning disability
(Fioritti et al., 1997; Guthrie & Roddam, 2011; Soroudi et al., 2007)
- Parkinson's disease
(Mittleman & Wetli, 1982)

Physical problems - specific

- Dysphagia
(Appelbaum, Bazemore, Tonkonogy, Ananth, & Shull, 1992; Berzlanovich et al., 2005; Cleary & Hopper, 2010; Ekberg & Feinberg, 1992a; Guthrie & Roddam, 2011; Hadjikoutis, Eccles, & Wiles, 2000; Warner, 2004)
- Presbyphagia
(Shemansky, 1991)
- Damage or deformity [orally/thoracic]
(Thacker, Abdelnoor, Anderson, White, & Hollins, 2008)
- Severe physical disability
(Guthrie & Roddam, 2011; Thacker et al., 2008)
- Oesophageal/reflux problems
(Fioritti et al., 1997; Pradeep Kumar, Venkatesh, & Jagannatha, 2008; Thacker et al., 2008)
- Impaired respiratory function
(Cleary & Hopper, 2010; Thacker et al., 2008)
- Impaired sensory- motor coordination
(Cleary & Hopper, 2010)

Physical problems – general

- Advanced age
(Berzlanovich et al., 2005; Bradway, 1996; Cleary & Hopper, 2010; Ekberg & Feinberg, 1992b; Fioritti et al., 1997; Shemansky, 1991)
- Poor physical condition, & debilitating diseases
(Bradway, 1996; Fioritti et al., 1997; Roy, Stemple, Merrill, & Thomas, 2007; Shemansky, 1991)
- Poor or absent dentition, dentures & poor oral care

(Berzlanovich et al., 2005; Cleary & Hopper, 2010; Ekberg & Feinberg, 1992b; Pradeep Kumar et al., 2008; Wick et al., 2005)

- Cardiovascular changes
(Shemansky, 1991)
- Poor health care
(Warner, 2004)
- Fatigue
(Guthrie & Roddam, 2011)

Person related – Cognitive/Behavioural

Cognitive

- Lack of insight
(Wick et al., 2005)
- Impulsivity
(Finestone, Fisher, Greene-Finestone, Teasell, & Craig, 1998; Snyder, 2009; Wick et al., 2005)
- Lack of reading skill
(Thacker et al., 2008)
- Lapses in concentration
(Ekberg & Feinberg, 1992b)
- Dementia related (using utensils inappropriately, unable to recognize food, forget voluntary steps, inability to initiate swallow)
(Bradway, 1996)
- Low intelligence
(Fioritti et al., 1997)

Behavioural - client

- Fast eating
(Appelbaum et al., 1992; Balandin, Hemsley, Hanley, & Sheppard, 2009; Berzlanovich et al., 2005; Fioritti et al., 1997; Pradeep Kumar et al., 2008; Thacker et al., 2008)
- Gorging
(Appelbaum et al., 1992; Balandin et al., 2009)
- Overeating
(Balandin et al., 2009; Fioritti et al., 1997; Pradeep Kumar et al., 2008)
- Non food items in mouth
(Thacker et al., 2008)
- Eating in secret
(Thacker et al., 2008)
- Eating on the move
(Thacker et al., 2008)
- Stealing food
(Thacker et al., 2008)
- Poor chewing
(Pradeep Kumar et al., 2008)
- Alcohol with psychotropic medication
(Fioritti et al., 1997)
- Non compliance
(Appelbaum et al., 1992; Snyder, 2010a)
- Institutionalisation and behaviour
(Aldridge & Taylor, 2012)
- Alcohol
(Berzlanovich et al., 2005; Wick et al., 2005)

Treatment related

Treatment

- Texture modified diets
(Berzlanovich et al., 2005; Ekberg & Feinberg, 1992b)
- Medications (side effects or sedation or both)
(Aldridge & Taylor, 2012; Bradway, 1996; Craig & Richardson, 1982; Thacker et al., 2008; Warner, 2004; Wick et al., 2005)
- Restraints
(Bradway, 1996)
- Not receiving recommended texture modified diet
(Balandin et al., 2009; Gatto & Delaney, 2008; Tammelleo, 2007; Tanner, 2010)

Environment related

Environment

- Distractions
(Cleary & Hopper, 2010)
- Level of support
(Tammelleo, 2010)

Psychosocial

- Fear of others stealing food
(Thacker et al., 2008)
- 'Desirable' activities scheduled after meal times e.g. cigarettes
(Guthrie & Roddam, 2011)
- Psychological adjustment to disability
(Bradway, 1996)
- Anxiety
(Hadjikoutis et al., 2000)
- Alcohol (behavioral, sedative, motor planning/sequencing)
(Ekberg & Feinberg, 1992b)

Organisational

- Level of supervision
(Cleary & Hopper, 2010; Gatto & Delaney, 2008; Tammelleo, 2007)
- Delegation to unskilled staff
(Snyder, 2010b; Tammelleo, 2007)
- Procedures e.g. clearing food too quickly
(Fioritti et al., 1997)
- Communication
(Tammelleo, 2010)
- Agency/new staff
(Guthrie & Roddam, 2011)
- Code status being verified
(Snyder, 2009)
- Lack of or poor assessment
(Balandin et al., 2009; Gatto & Delaney, 2008; Tammelleo, 2007, 2010)
- Prior history of choking ignored
(Gatto & Delaney, 2008)
- Flawed care plans
(Gatto & Delaney, 2008)
- Insufficient staff
(Gatto & Delaney, 2008)
- Lack of appropriately trained staff
(Gatto & Delaney, 2008)

Carer skills related

Staff Skills

- Awareness of choking risk (Finestone et al., 1998)
- Feeding skills (Cleary & Hopper, 2010)
- Not following care plans (Snyder, 2009; Tammelleo, 2007)
- Identification of choking (Berzlanovich et al., 2005)
- Basic Life support skills (Finestone et al., 1998)
- Application of BLS in challenging situations (Guthrie & Roddam, 2011)
- Speech pathologist competency (Tammelleo, 2010)
- Positioning (Cleary & Hopper, 2010)

Family Skills

- Providing care (Finestone et al., 1998)

Quality of life related

Autonomous decisions

- Refusal of treatment TMD (Snyder, 2010a)
- Refusal of supervision (Snyder, 2010a)

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Appendix 2

Outline of coronial process

Magistrates Court of Tasmania: Flow chart on the coronial process

Accessed from the Magistrates Court of Tasmania website: 07/11/2017 Search: Flow chart of the coronial process

http://www.magistratescourt.tas.gov.au/about_us/coroners/coronial_practice_handbook/introduction_the_coroners_court/flow_chart_of_the_process

Figure 1 is a flow chart of the most common way in which a coronial matter proceeds following a recent death.

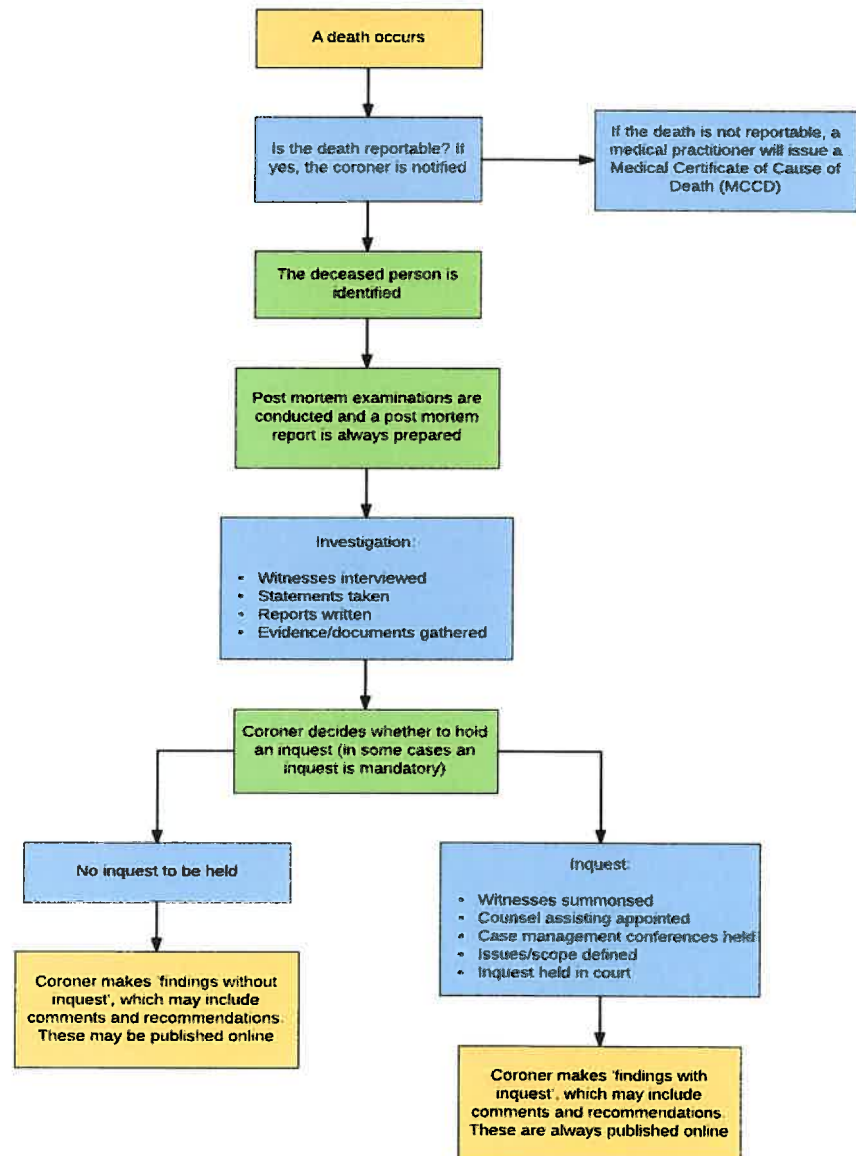


Figure 1 is a flow chart explaining a coronial investigation into a recent death. When a death occurs, either a doctor will write a Medical Certificate of Cause of Death or the death will be reported to the coroner. If the death is reported, a pathologist conducts post mortem examinations on the deceased person. If the death remains in the category of reportable deaths after this, the coroner will conduct a full investigation. If the legislation mandates it, or the coroner believes it is necessary, the coroner will hold an inquest. After the inquest or investigation, the coroner will write "findings" which may be published on the Magistrates Court web site.

Appendix 3

Ethics approval Letters

29 February 2012

Dr Stella Stevens
School of Medicine
Private Bag 34
Hobart TAS 7001

Dear Dr Stevens,

REF NO: H12275

TITLE: Choking management in people with dysphagia (swallowing problems), the balance between quality of life and death prevention: An analysis of coronial investigations into choking deaths in Australia 2000-2010

- *Application Form- Tasmanian Health and Medical HREC Low Risk*
- *Privacy Form*
- *Covering letters to the Committee*

The Tasmania Health and Medical Human Research Ethics Committee considered and approved the above documentation on **22 February 2012**.

All committees operating under the Human Research Ethics Committee (Tasmania) Network are registered and required to comply with the *National Statement on the Ethical Conduct Human Research* (NHMRC 2007).

Therefore, the Chief Investigator's responsibility is to ensure that:

- (1) The individual researcher's protocol complies with the HREC approved protocol.
- (2) Modifications to the protocol do not proceed until **approval** is obtained in writing from the HREC.
- (3) Section 5.5.3 of the National Statement states:

Researchers have a significant responsibility in monitoring approved research as they are in the best position to observe any adverse events or unexpected outcomes. They should report such events or outcomes promptly to the relevant institution/s and ethical review body/ies and take prompt steps to deal with any unexpected risks.

The appropriate forms for reporting such events in relation to clinical and non-clinical trials and innovations can be located at the website below. All adverse events must be reported regardless of whether or not the event, in your opinion, is a direct effect of the therapeutic goods being tested. http://www.research.utas.edu.au/human_ethics/medical_forms.htm

(4) All research participants must be provided with the current Patient Information Sheet and Consent Form, unless otherwise approved by the Committee.

(5) The Committee is notified if any investigators are added to, or cease involvement with, the project.



Tasmania
Explore the possibilities

(6) This study has approval for 4 years contingent upon annual review. A *Progress Report* is to be provided on the anniversary date of your approval. Your first report is due **13 February 2013**. You will be sent a courtesy reminder closer to this due date.

(7) A *Final Report* and a copy of the published material, either in full or abstract, must be provided at the end of the project.

Should you have any queries please do not hesitate to contact me on (03) 6226 1956.

Yours sincerely

Adele Kay
Acting Executive Officer
Health and Medical Human Research Ethics Committee
Human Research Ethics Committee (Tas) Network



Coroners Court of Victoria

65 Kavanagh Street Southbank 3006

T 1300 309 519

F 1300 546 989

W www.coronerscourt.vic.gov.au

CCOV RC Ref: 115

NCIS Ref: M0248

Ms Natalie Johnson

Manager, NCIS

Via email: natalie.johnson@ncis.org.au

Dear Natalie

Letter of Endorsement

Project Name: Choking management in people with dysphagia an analysis of coronial investigations into choking 2000-2010 (renewal)

The Coroners Court of Victoria (CCOV) Research Committee has now considered the request for access to coronial data in relation to the above-referenced research project.

I have now considered the application, along with the recommendations from the Committee, and am pleased to advise that I am granting renewed access the University of Tasmania access to Level 1 Victorian coronial data.

Please also note that my approval is subject to the University of Tasmania obtaining:

1. Approval from the DOJ Human Research Ethics Committee for this research project

If you have any other questions, please contact the CCOV Research Committee, Executive Officer, on 8688 0734.

Yours sincerely

Judge Ian Gray
State Coroner

31/7/15



Department of Justice

Justice Human Research Ethics Committee

Level 21
121 Exhibition Street
Melbourne, Victoria 3000
GPO Box 123A
Melbourne, Victoria 3001
Telephone: (03) 8684 1514
Facsimile: (03) 8684 1525
DX 210077

3 February 2012

Reference: CF/12/1569

Dr Stella Stevens
University of Tasmania

Re: Choking management in people with dysphagia (swallowing problems), the balance between quality of life and death prevention: An analysis of coronial investigations into choking deaths in Australia 2000 - 2010

Dear Dr Stevens,

I am happy to inform you that the Department of Justice Human Research Ethics Committee (JHREC) considered the project **Choking management in people with dysphagia (swallowing problems), the balance between quality of life and death prevention: An analysis of coronial investigations into choking deaths in Australia 2000 - 2010** at its meeting on 31 January 2012 and granted **full approval** for the duration of the investigation. Note that the researcher checklist needs to be signed by the Principal Researcher and sent to the JHREC.

The Department of Justice reference number for this project is CF/12/1569. Please note the following requirements:

- To confirm JHREC approval sign the Undertaking form attached and provide both an electronic and hardcopy version within ten business days.
- The JHREC is to be notified immediately of any matter that arises that may affect the conduct or continuation of the approved project.
- You are required to provide an Annual Report every 12 months (if applicable) and to provide a completion report at the end of the project (see the Department of Justice Website for the forms).
- Note that for long term/ongoing projects approval is only granted for three years, after which time a completion report is to be submitted and the project renewed with a new application.
- The Department of Justice would also appreciate receiving copies of any relevant publications, papers, theses, conferences presentations or audiovisual materials that result from this research.
- All future correspondence regarding this project must be sent electronically to ethics@justice.vic.gov.au and include the reference number and the project title. Hard copies of signed documents or original correspondence are to be sent to The Secretary, JHREC, Level 21, 121 Exhibition St, Melbourne, VIC 3000.

If you have any queries regarding this application you are welcome to contact me on (03) 8684 1514 or email: ethics@justice.vic.gov.au.

Dr Yasmine Fauzee
Secretary,
Department of Justice Human Research Ethics Committee



Department of Justice & Regulation

Justice Human Research Ethics Committee

Executive Services
Level 24
121 Exhibition Street
Melbourne, Victoria 3000
GPO Box 123A
Melbourne, Victoria 3001
Telephone: (03) 8684 1514
www.justice.vic.gov.au
DX 210077

5 June 2015

Reference: CF/15/10376

Prof Fran McInerney
University of Tasmania

Re: Choking management in people with dysphagia (swallowing problems), the balance between quality of life and death prevention: An analysis of coronial investigations into choking deaths in Australia 2000-2010

Dear Prof McInerney,

The Department of Justice & Regulation Human Research Ethics Committee (JHREC) considered your renewed application for the project *Choking management in people with dysphagia (swallowing problems), the balance between quality of life and death prevention: An analysis of coronial investigations into choking deaths in Australia 2000-2010* at its meeting on 4 June 2015 and granted **full approval** for the duration of the investigation. The renewed project has been issued with a new Department of Justice reference number – **CF/15/10376**. Please note the following requirements:

- To confirm JHREC approval sign the Undertaking form attached and provide both an electronic and hardcopy version within ten business days.
- The JHREC is to be notified immediately of any matter that arises that may affect the conduct or continuation of the approved project.
- You are required to provide an Annual Report every 12 months (if applicable) and to provide a completion report at the end of the project (see the Department of Justice & Regulation Website for the forms).
- Note that for long term/ongoing projects approval is only granted for three years, after which time a completion report is to be submitted. The project must be renewed with a new application before the initial three year period has expired.
- The Department of Justice & Regulation would also appreciate receiving copies of any relevant publications, papers, theses, conferences presentations or audiovisual materials that result from this research.
- All future correspondence regarding this project must be sent electronically to ethics@justice.vic.gov.au and include the reference number and the project title. Hard copies of signed documents or original correspondence are to be sent to The Secretary, Justice Human Research Ethics Committee, Level 24, 121 Exhibition Street, Melbourne, VIC 3000.

If you have any queries regarding this application you are welcome to contact me on (03) 8684 1514 or email: ethics@justice.vic.gov.au.

Yours sincerely

Nicole Wilson
Secretary,
Department of Justice Human Research Ethics Committee



CORONER'S COURT OF WESTERN AUSTRALIA

OUR REF: EC09/12
YOUR REF: M0248

Dr Stella Stevens
Acting Head Associate Head of Postgraduate Studies
School of Medicine
University of Tasmania
GPO Box 252 - 68
HOBART TAS 7001

By facsimile: (03) 6226 4784
By e-mail: Stella.Stevens@utas.edu.au

18 December 2012

Dear Dr Stevens

APPLICATION FOR LEVEL 1 ACCESS TO WA CORONIAL DATA VIA NCIS

Thank you for your application for access to coronial data which was considered by the WA Coronial Ethics Committee at its meeting on 27 November 2012.

The State Coroner, at the recommendation of the Committee, has approved your application subject to the following conditions:

- i. access be for a period of three years;
- ii. that only the named applicants be 'authorised persons' for the purposes of access (and the Committee be notified of any changes in writing); and
- iii. at the end of the three year period, the Committee will require notification about whether the needs and applications for the data have changed, so as to assess whether any changes in the form of the original application are required (although an entirely new application will not necessarily be required); and
- iv. the applicant is to provide the Committee with an annual report or update on the progress of the research.

Please also be advised that the Committee was also particularly concerned with the arrangements you will make to have the data securely stored – both in its paper format, and in its electronic form (hard drive, USB or otherwise). For that reason, it would be appreciated if you could write to the Committee, at the same time you provide your annual report, and provide an update about how security is being handled.

Please be advised that items such as full police reports and post mortem reports from Western Australia will not be able to be accessed on the NCIS. If this information is essential, a full further application will be required.

Should you have any questions, please do not hesitate to contact me on (08) 9425 2900.

Yours faithfully,

Kate Ellison
Secretary Coroners Committee

cc Joanna Colsonis
NCIS Access Liaison Officer
VIFM
57-83 Kavanagh Street
SOUTHBANK VICTORIA 3006
E-mail: joannac@vifm.org



CORONER'S COURT OF WESTERN AUSTRALIA

OUR REF: EC19/2015 [R09/2012]

Professor Fran McNerney
University of Tasmania

CARE OF NCIS

21 December 2015

Dear Professor

Application to renew access to WA Coronial Data via NCIS

I refer to your application to the Coronial Ethics Committee seeking to renew your access to WA NCIS data. Your application was considered at the Committee meeting on 10 December 2015.

The State Coroner, at the recommendation of the Committee, has approved your application subject to the following conditions:

- i. access be until 9 December 2018;
- ii. that only the named investigators be 'authorised persons' for the purposes of access (and the Committee be notified of any changes in writing); and
- iii. you shall, as soon as possible, **notify me of your full and correct contact details**;
- iv. at the end of the three year period, or the completion of the project, the Committee **will require** notification about whether the needs and applications for the data have changed, so as to assess whether any changes in the form of the original application are required (although an entirely new application will not necessarily be required); and
- v. the applicant is to provide the Committee with a **progress report, and/or any publications in which the data is published**, by 9 December 2015 **2016**

I can advise you that items such as full police reports and post mortem reports from Western Australia will not be able to be accessed on the NCIS. If this information is essential, a further application will be required in order for arrangements to be made for an approved person to attend the Court in person and to view its files. This will require the submission, to the Ethics Committee, of a curriculum vitae, and current police criminal record check, for each person being nominated.

Should you have any questions, please do not hesitate to contact me on (08) 9425 2900.
Yours faithfully,

Kate Elson
Secretary - Coronial Ethics Committee

cc **Jessica Bryan**
Acting NCIS Access Liaison Officer
NCIS, Department of Justice
65 Kavanagh Street
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Appendix 4

Example of Memo

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Memo on 'First Aid Challenges' category

<p>Knowledge category (anything to do with lack of specific knowledge)</p> <ul style="list-style-type: none"> Relationship between swallowing/eating problems and choking (017, 138) Signs/misdiagnosis of choking (144) Applying first aid/calling ambulance (027,252,076) Role of individuals during first aid procedure when multiple staff are present (218) How or when to use suctioning and oxygen (217) – could go in technique category Resuscitation status (43, 94) Need to provide aftercare (036, 217) Effect of choking on resuscitation attempts e.g. chest won't rise if full obstruction (183) – under technique may be
<p>Technique category (anything that relates to the specific application of elements of current or past first aid, anything used as a technique not currently recommended)</p> <ul style="list-style-type: none"> Choosing the appropriate technique; Heimlich, lateral thrusts or chest thrusts (189, 222) Not checking mouth to see if obstruction could be removed (159) Dismissing choking as cause of problem when obstruction not visible (166, 055) Use of finger sweep, effective at removing visible material but problems with pushing obstruction down further, jaw clenching, and victim biting down (173, 061, 174, 084, 109, 213, 227, 183, 221) Rubbing or patting back instead of hitting and applying blows in wrong position (029, 188) Giving the person a drink (182, 72, 044, 084, 114) Correct positioning during and after e.g. when to use recovery position (144) Doing standard first aid on non-standard bodies e.g. obesity, spine deformities (202) Limitations of carers e.g. height, strength (202) Removing person from room (162, 089)
<p>Physiology category (anything physiologically related- specifically the at-risk adult)</p> <ul style="list-style-type: none"> Absent or ineffective (weak) cough reflex and fatigue (144) Possibility of secondary events due to poor clearing (182, 69, 182, 229, 049, 144, 179, 077) Obstructions often in pharynx area and not visible (058, 062, 070) Immediate collapse with no lead up to unconsciousness or time to summon aid (017, 108, 130) Cognitive difficulties leading to lack of awareness or severity of choking (024, 049, 159, 229) General body issues and physical reactions (008, 144, 202, 028)
<p>Occupational safety category (anything that puts carer at-risk)</p> <ul style="list-style-type: none"> Trying to remove food/object from mouth (221) Risk of victim collapse and possible impact on carer (68, 024, 218, 202) Access to phone (010)

Commented [HMJ1]: The issues in this could form the basis for training content

Commented [HMJ2]: The issues in this might explain literature suggestions that basic first aid isn't sufficient see Guthrie paper

Commented [HMJ3]: This is in the literature

Commented [HMJ4]: This could also go under supported accommodation categories: orientation; communication/documentation; policies and procedures

Commented [HMJ5]: Really interesting that first aid techniques stop when suction arrives in most cases? evidence of effectiveness of suction over techniques, I would query whether suction units in most places would be powerful enough to remove solid obstructions, technology by default considered superior, coroners seem very focused on whether suction was available and used. Another research project here for a RN or first aid expert!

Commented [HMJ6]: Really interesting stuff here whether DNR stops first aid and intervention in choking, whether it should and how it is viewed depending on setting. see specific coroners views on this also relate to advance care planning/directives. Fundamental issue underlying reason for DNR could be relate to choking do people see choking differently because it is so easy to fix!!!

Commented [HMJ7]: Maybe beyond first aid

Commented [HMJ8]: No coronial comment on which technique used

Commented [HMJ9]: Links frailty of person, thinking that would help, fear of punishment if hurt person, physical strength of carer, providing comfort not intervention

Commented [HMJ10]: Note the possible clash here between speech path advice and first aid advice in relation to the possibility of a food still lining the pharynx and the possibility of 2ndry events

Commented [HMJ11]: Good intentions but making things worse category, start looking for whether such actions delayed the application of first aid

Commented [HMJ12]: Red highlight relating to things that prevent the possibility of intervention – consider environment

Commented [HMJ13]: Not currently recommended in conscious victims but done in conscious person, from training carers say they will do, because they can see it or they care about person and will risk being bitten – look out for this

Commented [HMJ14]: For heavens sake give carers a break bad enough they are not trained, not paid enough and left alone they can't even have access to a phone!!!!!!

Behaviour category (any behaviour of at-risk adult or carer that gets in the way of identifying choking or applying first aid)

- Lack of visible distress due to cognitive problems (049)
- Lack of insight of person leading to false reporting (213)
- Not seeking help (204)
- Placing non-food items in mouth (199, 191, 215, 159)
- Secretive behaviours e.g. stealing food from other people's rooms, furtive eating (024, 106)
- Continuing to place food in mouth when choking (084, 183, 029, 024)
- Isolating self from aid e.g. leaving the room (231, 064, 029, 148)
- Outings leading to unsafe food choices (068)
- Excess alcohol use (233, 256, 234)
- Carer panic (024)
- Lack of carer knowledge despite previous involvement in choking event (217)
- Carer not supervising (223)
- Carer prioritising other duties over supervision (011, 198,)
- Carer leaving the person after the event and not monitoring (217)

Faulty assumption category (any misconception that may get in the way of identifying doing first aid)

—Note to self, be careful here you are getting close to supposition, your training experience may be colouring what you are reading so keep that in mind

- Dismissing signs of choking as normal for the person e.g. coughing (209, 220)
- People with cognitive problems can reliably self monitor their behaviour (229, 029, 039)
- People can reliably report problems (068)
- If person has eaten food before it must be safe (227)
- If you can't see the obstruction then there isn't one (166)
- There can only be one obstruction (182, 069)
- People will show panic if choking (207, 108)
- If person has survived previous choking events they will continue to do so (220)

Commented [HMJ15]: Have to abandon the absolute that choking is a horrible way to die – nice possible finding for our people with dementia may be

Commented [HMJ16]: Poor mouse

Commented [HMJ17]: Perhaps if we didn't put them on highly restrictive diets this would happen less. ?let them have their high risk food somewhere pleasant where help is available if they need it.

Commented [HMJ18]: Cognitive or sensory problems?

Commented [HMJ19]: Note this was a problem in people with and without cognitive problems? social embarrassment ?physical feel they are going to vomit

Commented [HMJ20]: Look at this in more detail re the whole concept of special treats, breaking out of a rule driven environment, who the person is with family? Should the supported accommodation police this?

Commented [HMJ21]: Really interesting ??? linked with denial, if I don't know what to do I won't be held responsible?

Commented [HMJ22]: Keep this one in mind some interesting stuff here between failing to supervise, responding to other medical issues

Commented [HMJ23]: This is linked with some other data that is on the border of lack of awareness and neglectful care.

Commented [HMJ24]: Such a hard one differentiating between aspiration vs respiratory conditions and for those refusing TM drinks and food it would be 'normal'. Also that fine line between coughing indicating a partial obstruction so do you call the ambulance every time

Commented [HMJ25]: A lesson for us re the multifactorial nature of choking. Food texture not the determining factor as we think/hope

Commented [HMJ26]: Such an important issue for our people

Commented [HMJ27]: Where is this going to fit in the scheme of things after all some will and they will go on to die of something else

Appendix 5

Issues that could inform training content

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Issues that could inform training content

Issues impacting on choking management

(case examples in brackets)

Knowledge issues of carers

- Not understanding relationship between swallowing/eating problems and choking (017, 138)
- Not knowing the signs of choking (144)
- Misdiagnosis (144)
- Not knowing how to apply first aid (027)
- Not knowing when to call ambulance (027, 252, 076)
- Staff not knowing their role when first on the scene or during first aid procedure when multiple carers are present (218)
- Not knowing how or when to use suctioning and oxygen (217)
- Not knowing resuscitation status (43, 94)
- Not understanding the need to provide aftercare (036, 217)
- Not knowing effect of choking on resuscitation attempts e.g. chest won't rise if full obstruction (183)

Technique issues

- Choosing the appropriate technique; Heimlich, lateral thrusts or chest thrusts (189, 222)

Checking the mouth

- Not checking mouth to see if obstruction could be removed (159)
- Dismissing choking as cause of problem when obstruction not visible (166, 055)
- Use of finger sweep, effective at removing visible material but problems with pushing obstruction down further, jaw clenching, and victim biting down (173, 061, 174, 084, 109, 213, 227, 183, 221)

Back blows

- Rubbing or patting back instead of hitting and applying blows in wrong position (029, 188)

Other

- Giving the person a drink (182, 72, 044, 084, 114)
- Correct positioning during and after e.g. when to use recovery position (144)
- Doing standard first aid on non-standard bodies e.g. obesity, spine deformities (202)
- Limitations of carers e.g. height, strength (202)
- Removing person from room (162, 089)

Physiological issues

- Absent or ineffective (weak) cough reflex and fatigue making it difficult for person to self-clear partial obstructions (144)
- Possibility of secondary events due to poor clearing of oropharyngeal area (182, 69, 182, 229, 049, 144, 179, 077)
- Obstructions often in pharynx area and not visible (058, 062, 070)
- Immediate collapse with no lead up to unconsciousness or time to summon aid (017, 108, 130)
- Mental processing difficulties in some victims leading to lack of awareness or severity of choking (024, 049, 159, 229)
- General body issues and physical reactions e.g. vomiting when struck on back,

cardiac problems, large bodies (008, 144, 202, 028)

Occupational health and safety issues

- Trying to remove food/object from mouth (221)
- Standing the person to do first aid despite risk of their collapse and possible impact on carer (68, 024, 218, 202)
- Access to phone (010)

Behavioural issues

Choking person's behaviour

- Lack of visible distress due to cognitive problems (049)
- Lack of insight of person leading to false reporting (213)
- Not seeking help (204)
- Placing non-food items in mouth (199, 191, 215, 159)
- Secretive behaviours e.g. stealing food from other people's rooms, furtive eating (024, 106)
- Continuing to place food in mouth when choking (084, 183, 029, 024)
- Isolating self from aid e.g. leaving the room (231, 064, 029, 148)
- Water (167, 020)
- Distracted (061)
- Outings leading to unsafe food choices (068)
- Excess alcohol use (233, 256, 234)

Carer's behaviour

- Panicking (024)
- Not taking responsibility to learn choking technique (staff member) despite previous involvement in choking event (217)
- Not supervising (223)
- Prioritising other duties over supervision (011, 198,)
- Leaving the person after the event and not monitoring (217)

Faulty assumptions

- Dismissing signs of choking as normal for the person e.g. coughing (209, 220)
- People with cognitive problems can reliably self- monitor their behaviour e.g. stop eating fast, gorging (229, 029, 039)
- People can reliably report problems (068)
- If person has eaten food before it must be safe (227)
- If you can't see the obstruction then there isn't one (166)
- There can only be one obstruction (182, 069)
- People will show panic if choking (207,108)
- If person has survived previous choking events they will continue to (220)

Appendix 5 cont.

Possible training content for choking management based on findings

Introduction <ol style="list-style-type: none">1. Context: evidence for increased risk of choking events in people with eating/swallowing problems2. Two phases of choking management: risk reduction; harm minimisation once event occurs3. Risk reduction difficulties: severity of swallowing problem; quality of life decisions
Basic Anatomy <ol style="list-style-type: none">1. Head and neck, swallowing process2. Protective mechanisms3. Difference between aspiration and choking4. Where obstructions can occur5. Definition and signs of partial and full obstruction
Basic First Aid <ol style="list-style-type: none">1. Demonstration and practice of technique for full and partial obstruction: self-clearing (coughing); checking mouth; leaning forward; blows between shoulder blades; chest thrust; CPR
Challenges to above and how to manage them <ol style="list-style-type: none">1. Lack of expected choking signs e.g. panic, distress2. Behaviour due to cognitive problems e.g. person hitting out, running away3. Behaviours of others e.g. other residents trying to give person a drink, bread etc4. People in wheelchairs (with or without strapping)5. People in bed6. People on the floor7. People standing8. Speed of collapse9. Physical differences between person and carers, e.g. height, strength10. How to manage physical issues11. Risks to carers e.g. manual handling, use of masks for CPR
The application of Resuscitation (CPR) <ol style="list-style-type: none">1. Discussion of a person's right to refuse resuscitation and first aid2. Who decides, legal decision makers and advance directives3. The responsibility of different staff roles if do not resuscitate orders exist or resuscitation status is unknown4. Documentation and communication needed5. Organisational policies6. Alternatives to CPR at end of life (palliative care)7. Impact on carers of Do not resuscitation orders in choking
Co-ordinating care <ol style="list-style-type: none">1. Roles of different staff2. When to use suction/oxygen3. When to call ambulance4. What ambulance service can do
If there is a death what will happen <ol style="list-style-type: none">1. Police will investigate2. Need to leave scene intact3. Coronial process (inquest, internal review or basic investigation)